

Residential Services/Housing for. People Living with HIV/AIDS

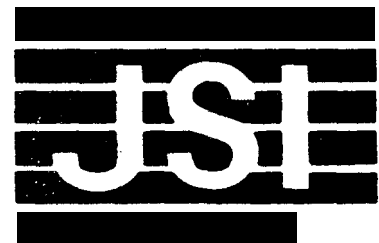
Analytic Synopsis

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The views expressed in this paper **are** those of the **authors**, not necessarily those of the **Bureau** of Health Resources **Development**.

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RESIDENTIAL, SERVICES/HOUSING FOR PEOPLE LIVING WITH HIV/AIDS

Executive Summary

People living with Human Immunodeficiency Virus (HIV) disease require a myriad of services to maintain a quality existence during their struggle with this debilitating and terminal illness. Housing and residential services play a critical role because they make a significant contribution to the success of other interventions, yet are often overlooked in the spectrum of services provided to people with HIV. Little is known, however, about the prevalence of housing and/or residential services for people with HIV disease, much less the implementation and operational issues associated with these services.

The Health Resources and Services Administration (**HRSA**) funded HIV Service Demonstration Programs (**SDPs**) in the late 1980s to develop and test the concept of comprehensive service delivery for people with HIV in contained locations. Residential services were among the spectrum of services offered in these programs. As **part** of their analysis of the demonstration programs, HRSA contracted with John Snow Inc. (**JSI**) to synopsize information and knowledge about residential services for people with HIV disease from these programs and others. Specifically, the research examined services provided in selected demonstration programs and in a few unfunded programs to identify and analyze the types of residential services offered and the issues associated with providing these services. This paper reports on the results of the research and offers policy recommendations related to residential services.

Methods

Data collection for the study included three components: literature review, site visits, and telephone interviews. The literature review revealed little with regard to persons with HIV. Populations with similar needs, such as the elderly and persons who are **mentally** ill or retarded, revealed some information that is applicable to the **HIV+/AIDS** population.

Five service demonstration sites were visited by the researchers. Each of these sites has (or had) a residential services component associated with the HRSA-funded Service Demonstration Program coalition. The sites are Broward County (Fort Lauderdale), Florida; Dallas, Texas; Hudson County (Jersey City), New Jersey; and Seattle, Washington; and Boston, Massachusetts. The sites were selected to represent a diversity of housing models and populations, but are not representative of the demonstration projects as a whole.

Telephone interviews with selected additional sites complemented the data collection from the site visits and the literature. Information similar to that collected in the site visits was solicited through an interview format. These programs were identified through compilations of housing programs that described the services provided and the populations served. Those selected represented geographical areas of significance for their experience with the epidemic or the specific barriers to care experienced that were not represented in the demonstration projects sites. These were projects in Mississippi, New York City, Denver, and Chicago.

Results/Discussion

The research resulted in a typography of the type of housing services available to persons with HIV at these demonstration sites. Seven different configurations were identified, some of which were distinct and clearly identifiable, and others which sometimes overlapped in the services offered or the issues they confronted. These seven configurations are described below in a spectrum beginning with the housing offering the least supportive services going to those with the most comprehensive services offered:

Shelter System

Description: The shelter system provides temporary lodging for persons who are homeless, typically in overnight shelters or in rooms in privately owned and publicly reimbursed hotels or motels. Dormitory style settings are generally available for adults without children, while families are usually housed in single rooms, with shared baths and no kitchens. Intended for homeless persons from all situations, people with HIV are integrated with others.

Implementation Issues: The primary purpose of the shelter system is to provide shelter, other services are minimal or non-existent (or if provided, are offered by an agency other than that operating the shelter). This housing is a temporary, unstable situation for residents. Infection control from other residents residing in close quarters is a concern for persons with HIV, as is discrimination by other residents and staff, which was observed in some settings.

Scattered Site Apartments

Description: Scattered site apartments are individual apartment units that are either formally or informally designated for use by persons with HIV. They may be grouped in one or a few apartment buildings or exist as single units scattered throughout a city or neighborhood. Leases are conducted in one of **two** ways: the tenant leases directly from the landlord, or an intermediary organization or agency leases the unit, and then sublets it to the tenant. Some apartments and/or tenants receive Section 8 subsidies for the rent on these apartments. Services are obtained on an individual basis by the tenant and are not provided through the housing provider/landlord.

Implementation Issues: Scattered site apartments are the most common type of housing for people with HIV in the sites researched. This configuration allows residents to maintain independence and choice over the location of their residence. It is the preferred option for families. The lack of support services can become problematic for residents as their illness progresses, as can the rental payments. From the provider's viewpoint, resource allocation for this type of housing can be flexible, varying the number of units available by the demand or need for them.

Congregate Living Facilities

Description: congregate living facilities are single homes housing a group of unrelated individuals (usually 5 to 7). In the sites visited, most are large private homes that have been converted into group quarters, with private bedrooms and shared common space (e.g., living room and kitchen). Residents pay rent to the agency operating the home, which usually also provides a live-in staff person. Services are provided by outside agencies, but often arranged by the sponsoring agency/staff person. These facilities are generally unlicensed and are intended as permanent residences.

Implementation Issues: The advantages of group living include increased peer support from housemates. The disadvantages include some loss of independence due to rules imposed by sponsoring agency (e.g., restrictions on smoking, alcohol, pets, guests). For these reasons, congregate settings are generally populated by gay men who apparently accept (or tolerate) the restrictions, and not by others living with the disease. They also tend to be inaccessible for non-ambulatory residents, or for residents who become non-ambulatory as their disease progresses.

Assisted Living Facilities

Description: Assisted living facilities provide housing and services on site, ranging from assistance with daily living to services just short of full-time skilled nursing. They target people with symptomatic HIV/AIDS who at minimum need assistance with daily living and may need medical monitoring. The settings can be a single family house, a larger facility with private rooms/suites, or a cluster of apartments in one or more buildings. These facilities are usually licensed.

Implementation Issues: Because of the availability of services, residents in these settings are often very ill and death is a frequent and stressful event for staff and other residents. These facilities generally have high operating costs, some of which are covered by third party reimbursements and/or by resident "rent" payments. Many of the facilities that were investigated were new configurations of residential services, thus requiring modifications in state licensure and reimbursement policies.

Skilled Nursing Facilities

Description: Skilled Nursing Facilities (**SNFs**) provide 24-hour, skilled nursing care. Residents are usually elderly persons, and persons with HIV are integrated into the existing population. A few dedicated HIV/AIDS **SNFs** exist.

Implementation Issues: SNF care produces a complete loss of independence for residents, who are treated as "patients," not "residents." The long-time focus of **SNFs** on the geriatric population has made it difficult for staff and residents to accept persons with HIV/AIDS. It is thus not the setting of choice for most persons with HIV, but may be the only option for those requiring extensive services. AIDS-designated **SNFs** seem to be more acceptable for persons with HIV, **especially** when they offer specialized services (e.g., nursing, therapy, etc.).

Residential Hospice

Description: Hospice services are usually provided in the patient's home, although some residential facilities exist, a few of which are dedicated for people with AIDS. Hospice provides palliative care for people at the end stage of their illness. They also provide grief and bereavement support for the patient, friends and family.

Implementation Issues: Because of the episodic nature of HIV disease and AIDS, it is difficult to determine when a person reaches the "end stage" of the illness, and thus would be appropriate for hospice care. In addition, much of AIDS care is considered curative, and thus must be sacrificed in order to receive hospice services (e.g., treatment for cytomegalovirus to prevent blindness). Of the sites examined, persons with AIDS tended not to use residential hospice services until very close to death, losing the benefit of bereavement and support services at which hospices are so successful.

Pediatric Residences

Description: Pediatric residences provide care for children usually as a temporary setting while the child awaits placement in a foster home or return to **their** family. They are typically categorized as assisted living facilities because many children reside in one house with an array of services provided on-site.

Implementation Issues: Pediatric residences typically do not accommodate families, except on a short-term, emergency basis, which creates a gap in residential options for families with children who are HIV+ and need supportive services. These homes, however, tend to be very well-funded compared to adult residences, with ample volunteers.

Conclusions

Examination of **the** HRSA-funded service demonstration projects supported the need for appropriate and accessible housing and residential services for persons with HIV. The demands and changing nature of this illness make stable housing an essential element in responding to the disease. Of particular note in our research was the lack of services for women and families, as **well** as appropriate services for persons diagnosed with substance abuse and/or mental illness in addition to HIV. The highlights of our findings follow:

Different people want/need different residential situations, and communities should offer a spectrum of options to effectively respond to these needs.

- Significant **gaps exist in** most cities in housing options and **services** for families, active substance users, and for mentally ill/ mentally retarded people with HIV.

As with other populations, people with HIV tend to prefer living situations which offer me most independence possible based on their stage of **illness**. In

the more structured settings, such as the congregate and assisted living facilities and the **SNFs**, rules should be kept to a minimum to balance resident safety with respect for independent choice.

- The cost of providing residential services have been seen to usually exceed revenues, particularly for congregate and assisted living facilities where services are often provided without commensurate third-party reimbursement.
- Federal and state laws, regulations and programs have in **some cases** been barriers to the development of housing for persons with HIV, and should be modified to eliminate these barriers.

In conclusion, residential services are an essential component in the spectrum of services offered to people with HIV. Efforts to develop these services and accurately direct them to people's needs would greatly benefit the quality of life of persons living with AIDS.

RESIDENTIAL SERVICES/HOUSING FOR PEOPLE LIVING WITH HIV/AIDS

Analytic Synopsis

I. INTRODUCTION

As people with AIDS live longer demand is increasing for living situations that are responsive and supportive through the entire course of a person's illness. Stable housing provides an essential base **for** services considered crucial to optimal health and well-being. Stable housing also provides a social forum for people who often feel isolated by their disease. **As** individuals secure a safe, comfortable residence, their emotional status stabilizes, they become more compliant with medical care and treatment, and they gain weight.' Housing appears to have an immediate impact on psychosocial and medical health and must be considered an important element in the full spectrum of care for persons with AIDS.

The housing and support service needs of persons with HIV/AIDS are defined by the episodic nature of HIV disease. People with HIV/AIDS experience a series of infections or other conditions that are more or less incapacitating. These severe illnesses, however, are usually short term; individuals often return to their previous physical state before the infection occurred. As a result, persons with HIV disease experience **continual** fluctuations in their housing and service needs. For instance, a person might be able to live independently most of the time, but need **24-hour** nursing care for one or two weeks to recover from an episode of pneumonia.

Individuals' needs also change over the full course of the **illness**. They are more independent during the initial stages, less independent as they approach the end stages. Housing options must be prepared to respond to the range of needs providing a spectrum of support services. Frequent changes in housing may exacerbate the illness or the person's condition, as well as place additional financial pressures on an individual already struggling with medical expenses. Continuity in housing is the ideal situation for persons with HIV/AIDS.

Although the study of housing in relation to HIV and AIDS is relatively new and directly relevant literature is sparse, many lessons can be learned from other populations needing supportive housing including the geriatric, mentally ill and mentally retarded populations. In these populations, functional assessment has become an important part of identifying appropriate housing options.* Attempts have been made to empower clients to establish their own networks and self-identity to improve their quality of life. Attempts have also been made to provide normal housing with specialized supports.' Agencies providing housing for mentally ill and mentally retarded populations have had to identify and confront stereotypical attitudes in communities where housing was located.' Based on the information collected in this study, all of these are appropriate concerns in HIV/AIDS housing.

This paper synthesizes data and information collected on housing for people with HIV disease between October, 1990 and December, 1991. Information was collected from three major sources:

1. Literature review: A review of current relevant literature on residential issues for people with HIV disease was conducted prior to the site visits and updated after the analysis. Since this field is relatively new and still developing, most of the information was obtained from abstracts of conference proceedings of the International AIDS Conference and the American Public Health Association. In addition, other populations with similar housing needs and issues were also explored for comparison (such as geriatric patients and persons with mental illness).
2. Site visits: In-depth site visits to five cities with Health Resources Services Administration (HRSA) funded HIV/AIDS Service Demonstration Programs contributed substantial information on housing models and issues related to people living with HIV disease. The five cities were: Boston, Massachusetts; Broward County - Ft. Lauderdale, Florida; Dallas, Texas; Hudson County - Jersey City, New Jersey; and Seattle, Washington. Each city had a number of sites providing housing services of various types, **all** of which were visited and analyzed by the research team. Collectively, the five cities represented a wide variety of housing models with diverse patient populations. The findings from these visits figure prominently in the synopsis of results.
3. Telephone interviews: Additional data were obtained through interviews with housing directors of projects in four other states. These projects contributed information about project implementation and operation.

The following discussion reports on the results of this research. It is a compilation of data and qualitative information gathered through the three sources described above.

II. CATEGORIES OF RESIDENCES FOR PEOPLE WITH HIV DISEASE

The research revealed an extensive range of housing models that varied according to location, number of residents, type of residents, supportive services provided, administrative and operational systems, and funding sources. For descriptive purposes, the extensive range is organized into seven major categories of residential settings for people with HIV disease: the shelter system, scattered site apartments, congregate living facilities, assisted living facilities, skilled nursing facilities, residential hospice and pediatric residences. In fact, while the majority of housing models can be described in one of these categories, the boundaries between the types are often blurred. Table 1 shows the category of each of the sites studied in this project. Table 2 illustrates the array of services available in each type of housing. This section describes each category studied in this project and discusses the implementation and operational issues typical of each.

**HRSA SERVICES DEMONSTRATION PROJECT
FACILITIES**

TABLE 1

Residential Formats	Facility Name	Location
Shelters	Anthony House May ... St. Lucies	Jersey City, NJ Jersey City, NJ ...
Scattered Site Apartments	Center I Think Life	Ft. Lauderdale, FL Ft. Lauderdale, FL
Congregate Living Facilities	Augustus House Beacon House De Wolfe House Payne House * Sandifer House *Horizon House	Jersey City, NJ Seattle, WA Seattle, WA Seattle, WA Jackson, MS D e n v e r , C O
Assisted Living Facilities	Amory St. Apartments * Bonaventure House Broward House Ewing & Revlon Apartments Plymouth Housing Grp. Apts. Rosehedge	Boston, MA Chicago, IL Fort Lauderdale, FL Dallas, TX Seattle, WA Seattle, WA
Skilled Nursing Facility	Bailey-Boushay	Seattle, WA
Residential Hospice	Hospice of Mission Hill	Boston, MA
Pediatric Residences	Bryan's House St. Clare's Home	Dallas, TX Jersey City, NJ

*Administrative staff from these facilities were interviewed by telephone.

Services Available Within HIV Housing Types*

TABLE 2

	Shelters	Scattered Site Apartments	Congregate Living Facilities	Assisted Living Facility	Skilled Nursing Facility	Residential Hospice	Pediatric Residence
Rental/Utility Assistance		.	.	.			
Mental Health Services			
Volunteer Support
Case Management	
Skilled Nursing Services					.	.	.
Homemaker Services				.			
24 Hour Supervision			
Pastoral Care			*in religiously sponsored homes		.	.	.
Home Health Care				.			
Meals
Substance Abuse Services						.	

*Services are generally, though not universally available as indicated

A. The Shelter System

Definition and Description

The shelter system is an existing emergency-bed system that was originally developed for use by homeless persons and is increasingly being used by homeless persons who are **HIV**-infected or have AIDS. Homeless shelters are found in every large city and in many smaller towns. Shelters include both overnight dormitory-type shelters that provide a bed for a **one**-night stay, and so-called "welfare hotels" where residents may remain for months at a time. In either case, the intent is to provide emergency shelter from life on the streets; all other services are ancillary.

Neither shelters nor hotels typically provide kitchen facilities; however, soup kitchens are often adjacent to the locations. Health care services are sometimes provided by a local homeless health care project sponsored by a community health center or a hospital and may consist of regular visits by a medical team to the shelter or hotel. A few cities provide respite care through their health care projects. In these cities, a homeless individual can stay at a respite care site throughout the day instead of having to leave the shelter in the morning and return in the evening. It should be emphasized that health care, meals and other supplemental services are not the primary services provided by the shelter system; a warm bed is offered and the rest is extra.

The shelter population is not HIV specific or segregated. That is, **all** people who are homeless make use of the system regardless of their health status. In general, overnight dormitory-style shelters are used by single men (and sometimes single women), whereas families are placed in hotels or special family shelters. Families are often given priority in services and slightly more desirable settings because of concern for the children. Families with HIV, however, are given no special treatment in the system beyond that given all families.

Implementation and Utilization Issues

Barriers to the use of shelters include limited accessibility because of limited number of beds and/or rooms; restrictions against people known to have HIV/AIDS; and lack of privacy and physical space; and waiting times (for rooms). There is **usually** a waiting list for a hotel room and individuals must wait in line on a **daily** basis to be admitted to the overnight shelters. It can also be difficult to locate a homeless person once their name comes to the top of a waiting list. In some cases a person can acquire a regular bed at an overnight shelter for a few weeks at a time, but this type of housing is generally not guaranteed and is at the discretion of the shelter operators.

Inadequate staff training on HIV/AIDS needs and care is also cited as a barrier to shelter use by those infected with **HIV**.⁵

The lack of permanency is a problem for infected or diagnosed **individuals** because of their rapidly changing health status. Someone in condition to survive on the street today might later need a month of bed rest to recuperate from an infection sufficiently to return to

homeless life. Persons infected with this disease need a stable living situation to adequately manage their medical condition.

In addition to the impermanent housing provided by shelters, people with HIV/AIDS are exposed to health concerns in this environment. Drug and alcohol use in shelters is a threat to the sobriety of persons in recovery from addictions, as is the case of many persons with HIV/AIDS. The lack of infection control procedures in many shelters is also a threat to the immune-compromised person with HIV/AIDS. For example, tuberculosis is becoming epidemic in the shelters and few facilities have adopted recommended preventative measures such as ultraviolet lighting and ventilation procedures. Finally, confidentiality of medical status to both the shelter staff and the co-residents is often lacking. When breaches exist, persons with HIV/AIDS can become stigmatized by other residents, as **well** as by insensitive and untrained staff. They may also be ostracized due to misinformation about contagiousness.

B. Scattered Site Apartments

Definition and Description

Scattered site apartments are the most common type of housing provided for people with HIV/AIDS. They are ordinary apartments or other rental units located throughout a city or town that are formally or informally designated for use by people infected with HIV or AIDS. The apartments may be located singly or multiply in houses or apartment buildings. They are managed in one of two ways: 1) An AIDS service organization (**ASO**) or individual activist serves as a broker or intermediary between property owners and prospective residents. The **ASO** or individual puts together a list of landlords willing to rent their units to people with HIV illness and then matches apartment seekers with available apartments. This process can range from giving a list of landlord names to apartment seekers to maintaining a database for individuals and social workers working with people with AIDS. 2) Alternately, an **ASO** solicits and signs leases with a number of property owners and then sublets the apartments to their HIV-infected clients. The organization, in this case, acts as the primary lease-holder of the apartment, does **all** the negotiating with the owner, and then acts as landlord to the residents. While both of these types of arrangements exist, the first type is more common. Many **ASOs** also provide limited, i.e., one to three month leases for people living independently or in scattered site units.

Implementation and Utilization Issues

There are advantages to scattered site apartments as housing for people with HIV/AIDS for both the residents and the housing supplier. Residents maintain a degree of choice in where they live (although the neighborhoods are sometimes different from residents' original locations), and they remain in a familiar living situation (i.e., living independently in a "regular" apartment). Residents in these apartments are usually provided services by the **ASO**, such as buddy systems, **meal** programs and referral services; however, residents make **all** arrangements for these services independently.

The housing supplier can invest as few or as many resources as available and desired to supply scattered site apartments. Intermediaries perform the important function, not only of helping to find the housing in the first place, but also continuing to maintain the infected person in a supportive system without providing intensive services or necessarily expending many resources.

Financially, scattered site housing is market-rate living accommodations, which can be subsidized through the use of section 8 certificates or directly from the intermediary when the intermediary is sub-letting to the resident. As residents' incapacitation increases with the progression of the disease, the financial burden of this type of housing can increase and some may be forced to move. For example, residents' need for home care services will increase, creating a financial burden. In summary, scattered site apartments are an easily implemented and useful option for many persons with HIV/AIDS, but need to be supplemented with other supportive services and types of housing to meet the needs of individuals in all stages of HIV disease.

C. Congregate Living Facilities

Definition and Description

Congregate living facilities are residences for groups of unrelated people living together in one house or building, sharing common space and sometimes activities. The primary purpose of a congregate facility is to provide a home for the residents and the support that derives from living with others in a similar life situation. The concept of congregate living has been developed for use by many populations, from homeless families to the elderly. The philosophy that accompanies congregate living is that a community environment can be developed in shared living space, and the community can be beneficial to the health or sustenance of the individuals who participate.

Most congregate homes for people with HIV/AIDS have been developed and/or sponsored by churches, community groups and/or concerned individuals. These groups may own or lease the congregate house, and they, in turn, create a contract or rental agreement with each resident. In a few cases, the group organizes and runs the house, but residents pay rent to and lease their room from another owner of the property. Although a spectrum of facilities exist, congregate residences are generally single family homes in which five to seven individuals reside in private bedrooms with shared kitchen, living and dining areas. In most cases, an external staff person or "houseparent" lives in the house to assist residents with medical arrangements and other responsibilities, and to assist the group in living together. However, in some cases the group is independent. The residents and the staff, if they exist, mainly provide social support to the residents; home health care, nursing services and other professional care is typically provided by external agencies that visit the house under independent arrangements with residents.

Residents in congregate housing maintain their independent status in so far as they make their own arrangements for care and manage their own affairs. Most congregate houses encourage residents to bring their own furnishings and personal belongings for their bedroom. Residents generally pay some form of rent to the agency sponsoring the house, but it is almost

always highly subsidized by the agency. While congregate facilities place a priority on providing a place to live for their residents in a residential setting, the services they may provide are generally supportive in nature (recreation, help with shopping, making appointments, limited support/counseling).

Implementation and Utilization Issues

Licensure of facilities becomes an issue whenever unrelated people reside in the same house. In general, congregate facilities have avoided licensure when possible to avoid the additional, often inappropriate, programmatic requirements that accompany the certification. On the other hand, a few houses have sought licenses solely for the purpose of improving their credibility with the community, funders or others.

Some congregate homes act as transitional housing for their residents, but most are intended as permanent residences. When this is the case, residents' progressive incapacitation due to HIV/AIDS can create medical and caretaking needs that may be difficult to accommodate in congregate homes. However, most congregate facilities encourage residents to remain in the house through the course of their disease and make efforts to secure necessary home health, meals and housekeeping assistance. The biggest obstacle to remaining in these homes seems to be physical accessibility for people who are not ambulatory. Many congregate homes are in single family houses with limited space on the ground floor and limited funding to make second floor bedrooms accessible. To their credit, however, most congregate facilities have made an effort to make at least one bedroom accessible.

In addition, the different stages of residents' illness may create discomfort for other residents, and may require greater staff intervention and assistance to the group (e.g., counseling in the case of deaths in the house). However, because many of these facilities are relatively new, they have yet to encounter the problem of multiple deaths.

Group living also brings up the issue of accommodating the different behaviors and lifestyles of residents. Despite the commonality of the disease, residents might find themselves faced with a variety of differences ranging from substance abuse to sexual orientation. Many of the congregate housing situations tend to be homogeneous: gay men, women, drug users. By far, most congregate homes are for gay men only. Mixed groups do occur, however, and will be more common as the epidemic develops. The need for staff assistance in group dynamics issues should be anticipated.

Congregate housing is one step beyond scattered site apartments in terms of support services offered. However, there is a loss of independence for residents in **this** setting. Most homes include significant rules regarding pets, smoking, alcohol, overnight guests, etc. Especially for relatively independent residents who wants some support in a group setting, these restrictions can be very burdensome and can discourage residents from moving into this setting except as a last resort.

D. Assisted Living Facilities

Definition and Description

Although there is not always a clear distinction between congregate living and assisted living facilities (**ALFs**), **ALFs** provide a higher level of skilled or custodial care for their residents. **ALFs** can be a single family house, a larger facility with numerous private rooms or suites, or a cluster of apartments within a larger building. The **ALFs** researched in this study were all devoted exclusively to persons with HIV/AIDS and generally purchased or leased by a sponsoring organization. Services run the gamut of care from simple assistance with daily activities, to care one step below in intensity of that received in a skilled nursing facility.

As with congregate homes, **ALFs** are not particular to people with HIV/AIDS; the model has been used for disabled persons and the elderly, among others. Assisted living facilities for persons with HIV/AIDS, however, serve this population exclusively. **ALFs** generally target the symptomatic AIDS resident who needs assistance with basic activities (e.g., dressing, hygiene, eating, etc.) and may need medical monitoring. Individuals with dementia are often housed in **ALFs** because of the level of assistance they require.

This type of housing meets the needs of the growing number of persons who can **live** relatively independently if they receive some **daily** support and assistance and can rely on the availability of more intensive assistance during acute phases of illness. Residents receive the communal support that exists in congregate homes, as well as the added support and care commensurate with more acute stages of illness. Residents generally live in an **ALF** for the duration of their lives once moving in. Deaths of residents are common and support is often provided by the hospice staff.

The services provided in this setting may be furnished by on-site staff or from outside contracted agencies. **ALFs** differ widely in the number of staff they maintain on-site, types of services the sponsoring agency provides through off-site staff, and types of services provided through external agencies. Services may include nursing, health aides, meal preparation and recreational services. The provision of services has significant financial implications for the facility, as discussed below.

Examples of three Assisted Living Facilities help to illustrate the range of residences under this heading:

*** Ewing Hall and Revlon Apartments -- Dallas, Texas: These two** adjacent apartment buildings, one with 19 available units (Ewing) and the other with 2-S units (Revlon), are owned and operated by AIDS Services of Dallas. Ewing Hall is mostly "efficiency units" designed for single occupancy with limited kitchen facilities. There is a congregate kitchen for evening meals. Revlon includes efficiency one and **two-**bedroom units with full kitchens. There are no congregate meal facilities. The units are operated under a "Special Care Facilities" license which requires **24-hour** staffing by personal care assistants. Skilled nursing services are provided by the Visiting Nurse Association four to eight hours per day. A program director manages an extensive

volunteer staff who organize social and recreational events and transportation to community food banks and coordinate with other community programs. The average length of stay at the facilities is 166 days, ranging from a few days to more than a year. The Revlon apartments, because of the size of their units, are able to house families. They have had 28 females and up to 11 children on site at a given time. The annual operating budget is currently \$700,000 but is estimated at \$1 million for 1992 and does not include the services of the agency's extensive volunteer network.

* **Broward House -- Ft. Lauderdale, Florida:** This is a **52-bed** facility of mostly double-occupancy rooms with a congregate kitchen and full-time cooking staff. It is operated under Florida's "Adult Congregate Living Facility" license. The license entitles Broward House to an Optional State Supplement (OSS) to resident's Supplemental Security Income (SSI) benefits raising the resident's monthly allotment from \$438 to \$575. Residents pay \$450 per month of this allotment as rent. The annual operating budget at Broward House is approximately 1.2 million of which approximately 20% is covered by rents. Average length of stay is 120 days with a range of two weeks to more than one year. Medical staff includes **24-hour** coverage by one licensed **practical** nurse and one nurse's assistant per shift. An RN supervisor is on staff days.

* **Rosehedge -- Seattle, Washington:** This is a **small** facility of two adjoining houses each providing residential care and services for six people. It also provides a greater level of care and assistance than either of the other two examples as its residents are fairly sick and many are bed-bound. The average length of stay is 45 days. Rosehedge is staffed by a cook, a psychiatric case manager and assistant, and an activities therapist, in addition to an RN and aide during the day and two aides, evenings and nights. It is operated under Washington's "Adult Family Home" license which entitles Rosehedge to receive reimbursement from the state's Aging and Adult Services program for room and board as well as Medicaid for health care related expenses. King County's Department of Mental Health also contributes a portion of the daily expense. The Rosehedge budget for 1992 is projected at approximately \$725,000 which is \$178 per bed day. Rosehedge expects to generate approximately \$164 of this through the various reimbursements noted above leaving approximately \$50,000 or \$13 per day to be generated through fundraising.

Implementation and Utilization Issues

Most **ALFs** are licensed due to regulatory requirements of their reimbursement sources. In some states, reimbursement for room and board, custodial, and medical services the staff provide to residents is contingent on the ALF being fully licensed to provide such care. They are financed through a combination of contributions from residents (generally a percentage of their Social Security benefits), service reimbursements from Medicaid or health insurance policies, and fundraising activities.

Operating costs for **ALFs** tend to be very high because of the level of services provided. To date, many of these facilities have supported their operating budgets with extensive fundraising efforts and relied only minimally on housing and service reimbursement sources. The future financial stability of these facilities may be in jeopardy if they maintain

their current financing strategies. On the other hand, one particular ALF has developed a strategy to recoup over 90% of its budget through reimbursements, indicating that the potential for considerable reimbursement exists, although the mechanisms for receiving it are often obscure.

The ALFs also encounter many psycho-social impacts of HIV/AIDS care in dealing with implementation and utilization issues. There is a fairly high turnover in ALFs since the residents arrive in the later stages of HIV illness. The staff, as well as residents, need the support of professional mental health services in dealing with the stress of multiple deaths.

E. Skilled Nursing Facilities

Definition and Description

Skilled nursing facilities (SNFs) are institutions that provide 24-hour nursing care to residents and are generally one step below an acute care hospital in terms of intensity of services. Nursing homes are most commonly inhabited by the elderly, and very few are dedicated to persons with AIDS. The integration of persons with AIDS has presented some problems, as discussed below.

SNFs are at the extreme end of the spectrum of housing options in terms of the intensity of care provided as well as the institutional nature of the setting. Residents of nursing homes tend to lose their independence and are treated as patients rather than residents. As a result, most persons with AIDS prefer not to live in this setting and have been generally successful in avoiding it. Financial limitations may enforce the nursing home option, however, in situations when other living arrangements are not available or are not reimbursed by insurers.

Implementation and Utilization Issues

Because SNFs have become so established as geriatric care centers, it has been problematic to adapt staff and resident attitudes to accepting individuals with AIDS. In addition, the young person in the final stages of AIDS is often reluctant to reside with an elderly population. There are also, in some cases, reputations of inconsistent care provided by SNFs. As a result, providers are sometimes hesitant to refer persons with AIDS to nursing homes. Despite these arguments against SNF placement, the practical situation of extremely limited bed availability may mean the option is not available regardless of its appropriateness.

Dedicated AIDS SNFs also present some barriers. Local organizers have in some cases encountered community opposition to locating this type of facility. Building codes and licensing regulations designed for other populations have also been troublesome for designers to overcome.

On the other hand, one city has been very successful in designing and developing an AIDS-dedicated SNF, garnering support from the business and social service community; Their success may be traced to remaining flexible in their planning process by acknowledging the fact that the epidemic might not support the need for their facility in the future, and their

plans include both additional services on-site as well as a regulatory and physical structure that could accommodate other types of patients if needed.

F. Residential Hospice

Definition and Description

Hospice provides palliative care to terminally ill individuals in the end stage of their lives, both at home and in a residential setting. Palliative care includes relief of symptoms and management of pain, without aggressive treatment. Hospice also provides grief and bereavement counseling and support to the individual and to family/friends. Most hospices are in-home; there are only a handful of dedicated AIDS residential hospices in the country, although many residential hospices and in-home agencies accept persons with AIDS.

Implementation and Utilization Issues

Despite early predictions to the contrary, persons with AIDS tend to shy away from residential hospice settings until very close to their death. One AIDS-dedicated facility has an average length of stay of about two weeks. An explanation for this situation is the existing hospice philosophy which holds that all care provided be strictly palliative. There is some controversy about whether care such as intravenous gancyclovir or foscarnet for cytomegalovirus (CMV) is in fact curative or could rather be considered palliative, but in the meantime persons with AIDS must forego many treatments if they choose hospice care.

In addition, because the nature of HIV disease is a series of generally treatable infections, it is difficult to define the point at which the disease enters its-"end stage." The result is that persons with AIDS often do not avail themselves of the grief and bereavement services that hospices are so successful at providing.

G. Pediatric Residences

Definition and Description

Pediatric residences generally fall into the assisted living facility category in that they are houses with many children residing at one facility and have a staff that provide an array of services to the "residents". Pediatric residences are all designed to be transitional; they are a place for children to live while awaiting foster placement or for a period of time until they can be reunited with their previous caretakers/homes. These residences tend to provide very intensive services and are aimed at actively assisting the future caretakers with accommodating children's special needs, regardless of whether they are returned to a home or placed with a new caretaker. Residences exist in virtually every city and many small towns and tend to be very well funded with an abundance of volunteer staff.

Implementation and Utilization Issues

Families are generally not accommodated in pediatric residences, nor in any of the other models discussed, creating a problem for the family that wishes to remain together.

Because children with HIV disease have generated much public sympathy, **public and** private funding for pediatric facilities has not been an obstacle. Similarly, many volunteers are available to augment paid staff in providing services to the children. The residences tend to be nicely furnished and in relatively good condition compared to those available for adults. They are exclusively a transitional setting for the children, as foster homes are, at this time, readily available in most areas. In general, there are fewer barriers in developing and operating these facilities than the adult residences. However, on-going fundraising is essential for these facilities as there is little reimbursement for many services.

III. DEVELOPMENTAL AND OPERATIONAL ISSUES

A. Financing

Financing of residential services involves both capital costs to purchase and develop the facility and operating costs to manage and run the facility. Capital costs are often donated by the sponsoring organization (such as a diocese or a city), or major fundraising campaigns are conducted in the community. Recently, the Department of Housing and Urban Development (HUD) made funds available for the development of housing for people with HIV disease. In the future this federal agency should be an important source of capital costs. At the time of this research, however, HUD programs were in their infancy and played only a very small role in financing HIV/AIDS housing.

The Health Resources and Services Administration provided capital for new construction and renovation of existing structures under the **1610(b)** program. This grant program was funded for four consecutive years and targeted three types of projects: hospital-based clinics, free standing facilities and community health centers. The **1610(b)** program required a local community or city/state matching of funds. The Bailey-Bouchay House received **1610(b)** funds for the development of a skilled nursing program as well as a day care program. These funds were generally not available for housing programs which were not medically focused.

In general, housing projects have had less difficulty raising capital funds than in funding on-going operations. Fundraising activities have tended to be successful, and as capital campaigns rely heavily on this source, they have been relatively easy. In contrast, raising operating funds through fundraising efforts is problematic. It is generally more difficult to do. In addition, it is financially inadvisable to rely on such a variable source of income for **day-to-day** expenses.

Operating costs include mortgage costs, utilities, insurance, staff salaries, food, equipment and supplies. Operating costs are an issue for all AIDS housing types but most particularly congregate and assisted living facilities. Shelters are publicly funded; scattered site apartments are paid for through rental income including public subsidies when available (although some agencies assume responsibility for a portion of the cost of scattered site apartments), and hospices and skilled nursing facilities are reimbursed through health insurers (**whether** that is **Medicaid**, Medicare or private insurance). Nationally, Medicaid, Medicare and insurance payments cover an average of 75 percent of hospice costs leaving a shortfall of 25 percent.

Operating costs for congregate housing and **ALFs** are generally covered by a combination of resident contributions and external funding sources. Residents are asked to contribute a portion of their Supplemental Security Income (**SSI**) benefit toward rent payment. This contribution typically funds 25 to 40 percent of operating expenses. Health care and other services provided by staff or contract agencies may be funded directly by Medicaid or other insurers. In some cases contributions and fundraising income may be supplemented by programs or staff funded through the Ryan White Care Act or other state and local sources.

Without a consistent source of funding, financing operating costs is a continual effort at which many projects are not particularly successful. Sources differ by state and by population served. There is little guidance about the myriad of options, and as a result, financially strapped projects often overlook sources of funding.

Assisted living facilities generally have better reimbursement than congregate housing because they provide services which are more often reimbursable, and reimbursed at higher rates than housing alone. On the other hand, ALF costs are higher than those of congregate facilities (on average, \$2,500 to \$5,500 per resident per month for ALF versus \$600 to \$900 per resident per month for congregate). As a rule, however, **ALFs** tend to underestimate the revenue sources for their services. Many facilities underbill for the in-house counseling that is provided or do not adequately seek out sources for housing subsidies, for example. This oversight is often the result of an overworked staff, combined with a lack of knowledge of housing funding sources and/or medical reimbursement strategies.

The maze of subsidy and reimbursement mechanisms is so complex that it is virtually impossible to sort out, especially by an AIDS service provider-turned housing developer, as many of the executive directors of housing suppliers in this field are. Also, existing reimbursement mechanisms may require modification in order to accommodate HIV disease and AIDS. For example, in Dade County, Florida, if a resident of an ALF is bedridden for more than **48-hours** they are no longer eligible for continued stay and could lose their residency status. While these modifications have not generally been difficult to achieve, time and attention are required to identify specific legal or regulatory barriers and to work with policy makers to implement change.

While shelters, scattered site apartment, skilled nursing facilities and hospices are pre-existing facilities and generally integrate HIV/AIDS patients, congregate homes and assisted living facilities have been developed specifically for people with HIV disease. As a result, funding for these models has been more challenging because it is breaking new ground. Some examples follow to illustrate the range of funding strategies:

- The licensed congregate living facility in Broward County, Broward House, was envisioned by members of the North and South Broward County Hospital Districts, Hospice Care of Broward County and community AIDS advocates and activists. Through a lobbying effort they were able to receive the support of the Broward Legislative Delegation and received a one time allocation of 1.5 million for the purchase of the **52-bed** facility. As a result, the facility is essentially debt-free excluding operational expenses. Eighty percent of the facilities operating budget is

realized through grants, donations and fundraising. Resident income from rents is \$450 per month per resident, which amounts to the remaining twenty percent of the budget.

Ewing **Hall** and the Revlon Apartments in Dallas, Texas are both licensed by the Texas Department of Health. The Ewing facility is a group of efficiency apartments. This building was purchased with a private contribution of \$175,000 to the Dallas People with AIDS Coalition. On an adjacent lot, the one- and two-bedroom Revlon Apartments were purchased with a contribution of \$33,000 from the Dallas Design Industry Foundation for AIDS (DIFA). This is one of the few **ALFs** in the country that accepts families. The facility receives Ryan White II funds to cover the cost of a home health aide and other support staff. Rental income supplements these funds and accounted for \$30,000 of a \$700,000 annual budget last year.

The **Amory** Street Supervised Apartment Program in Boston is funded by the Massachusetts Department of Public Health, AIDS Bureau in collaboration with the Department of Public Welfare and the Boston Housing Authority (**BHA**). These agencies provide the funds through a not-for-profit organization providing comprehensive community-based services to individuals with disabilities. The state also uses Ryan White funds to support the staff of two **24-hour** home health aides, a **part-time** registered nurse, and the program director and program manager. The residents pay up to 30 percent of their income towards rent. There is an allowance for medical deductions from this 30 percent. The remainder of rent comes from federal dollars provided through the BHA.

• Skilled nursing facilities were in existence prior to the HIV epidemic, providing care to a mostly geriatric population. This continues to be their major focus, causing difficulty in securing **SNF** beds for people with AIDS and **also** leading to some discrimination toward persons with AIDS among both staff and patients. To encourage **SNFs** to accept people with AIDS, New Jersey provides an additional **daily** rate for the person with AIDS requiring skilled nursing care. One innovative program, the Bailey Boushay House, is under development by AIDS Housing of Washington. It is being designed as a skilled nursing facility and will be licensed through the Washington State Department of Social and Health Services. Approximately \$6.2 million has been raised toward construction and development with a significant grant from the Robert Wood Johnson Foundation and a low interest, long-term loan from a local bank. Funds have also been contributed by the city, county and state governments, **local** corporations and over 6,000 individual donors. The expected daily cost is \$212 per person, or about one-third of the average daily hospitalization rate.

Bryan's House, a pediatric residence in **Dallas**, is an eleven-bed facility with a day care component. It was started with concerned community AIDS advocates who recognized the increase in the number of pediatric AIDS patients who were left in hospitals. Through corporate sponsors and individual donations, they raised sufficient investment capital to purchase a house in a residential neighborhood. Through mostly corporate sponsors, the house has been redesigned with additional extensions to accommodate the various programs sponsored by Bryan's **House**.

St. Clare's Homes for Children are pediatric residences in Jersey City, Neptune and Elizabeth, New Jersey. These homes are managed by the AIDS Resource Foundation for Children who received an initial grant of \$150,000 from the New Jersey Department of Health to purchase the first residence. Loans and fund raising efforts were utilized in the purchase of the other residences. Their annual operating budget totals \$2.2 million for the three homes. One fourth of the budget comes from fundraising. The state department of Youth and Family Services funds staff costs of approximately \$300,000 per year, and provides reimbursement for certain services provided at the homes. Medicaid provides reimbursement for other services.

The Sandifer House in Jackson, Mississippi is a licensed personal care facility. The house was purchased with funds raised for a year through local gay bars. Including the mortgage on the house, the annual expenses total \$54,000. Residents contribute \$200 a month for room and board. Approximately \$15,000 is raised annually through events in gay bars.

Bonaventure House, an assisted living facility run by the **Alexian** Brothers in Chicago, is a thirty-bed residence. The annual budget is \$875,000 which includes expenses related to the current capital campaign. Program costs total ~~\$55-\$60~~ per person per day; including administrative costs, the cost per person per day is ~~\$75-~~\$80. Bonaventure House receives 35 percent of its funding from government sources, 30 percent from corporations, 10 percent from resident fees, 10 percent from religious congregations, and 15 percent from direct mail and special events. Residents pay 45 percent of their income toward room and board, which averages \$175 per resident per month.

B. Sponsoring Organizations

As stated previously, most residential facilities are created by AIDS advocates and caregivers who identify housing as a need in their community and proceed to identify the appropriate setting and facility. The sponsoring organizations are churches and church coalitions, AIDS advocates with backgrounds in health care, gay coalitions and People, with AIDS Coalitions. Both the organizers and the sponsoring organizations usually lack housing development or operations experience, and as a result, are often naive about the intricacies of the field. They have little expertise in rental assistance programs or service reimbursement options and sometimes lack knowledge about networking with housing authorities or government agencies.

There are exceptions, however. AIDS Housing of Washington (Seattle) and the **Vinfen** Corporation (Boston) stand out as two organizations who brought AIDS-knowledgeable staff together with housing- and fundraising-knowledgeable staff. The result was a successful linkage of AIDS advocates, housing advocates and government agencies. Broward House is an example of fundraising and AIDS-knowledgeable staff pursuing **licensure** and regulatory change to address one piece of the housing issue in Florida. Successes such as these tend to incorporate housing expertise with a familiarity with the needs and nature of HIV disease.

C. Licensing

Certain types of residential facilities require licensure in order to operate and/or obtain reimbursement for services provided to residents.

Three types of facilities discussed in this report generally require licensing: skilled nursing facilities (**SNFs**), hospices, and assisted living facilities (**ALFs**). Congregate living facilities see themselves as private residences and have generally chosen to avoid licensure by limiting the number of residents and scope of services.

Licensure requirements for **ALFs** vary widely across states and sometimes across counties. For example, an ALF in Florida is licensed as an "Adult Congregate Care Facility," an ALF in Washington state is an "Adult Family Care Facility," and an ALF in Texas is a "Special Care Facility". Licenses for **ALFs** may define acceptable levels of resident disability, staffing patterns, facility layout, equipment, and supplies. They may determine reimbursement rates and the availability of certain subsidy or other funding programs. Compliance with licensure requirements also brings with it inspections and other official monitoring of operations, which can be burdensome to facilities. This effort must be balanced against the reimbursement opportunities and measure of public credibility that licenses offer.

It should be noted that most ALF licensure requirements were originally formulated to protect the quality of life and the safety of the disabled and elderly living in institutions or boarding houses. They are universally inappropriate for the HIV-affected population and must be modified when encountered. For example, the Adult Congregate Care License in Texas did not allow residents to be bed-bound for more than 7 days, while the Adult Family Care license in Washington did not permit pooling of residents' allowed- nursing hours to permit **24-hour** nursing coverage. To accommodate the needs of HIV/AIDS residents, both licenses had to be modified. It has been projects' experience that such modifications are not difficult to obtain; legislative and regulatory bodies have, to date, been very cooperative in granting approval for variations once the actual needs are determined. However, it requires knowledge, initiative and time to define and secure the needed modifications. It is a process that is not always tackled by community groups of church-based organizations who may be reluctant to battle the "red-tape".

The license for **SNFs** and hospices also vary from state to state. The **SNF license** essentially defines the standards of care to be incorporated in each SNF, including staffing patterns, criteria for residents to receive SNF care, reporting standards, and mechanisms for reimbursement for services provided at a daily rate. Hospice licensure determines the reimbursement rate as well as setting criterion for the duration of care and the type of patient who receives care.

In some cases licensure determines the clientele that can be served at a **particular** facility. For example, in Dallas, licensed adult day care providers must provide certain **skilled** interventions to clients. **In** order to accommodate persons with HIV disease who do not require such interventions (that is, persons in all stages of the disease including **those** who need the support of adult day care without skilled care) one day care provider chose to forego licensure for the sake of independence in choosing its clientele and service package.

Sacrificed, however, was the daily reimbursement rate tied to licensure. The facility must instead fund their program through private sources (donations and grants).

D. Government Housing Subsidy Programs

Federal dollars flowing into the states are distributed through a variety of offices and state-specific programs. Federal and state programs are available to support rental subsidies, capital improvements and residential services. Public housing developments that are subsidized by state and federal funding are managed and **owned by** local housing authorities. The U.S. Department of Housing and Urban Development (HUD) administers the federal funds and a state office of housing distributes money locally. Table 3 outlines the various HUD housing assistance programs that are targeting people with HIV/AIDS and other programs that target the homeless or low income people and could include people who are living with HIV/AIDS.

Several HUD housing programs are administered through the local housing authorities and the Federal Housing Administration (**FHA**). Section 221(d)(3) and Section 236 are programs for subsidized multi-family rental housing. These programs provide mortgage insurance for the construction or rehabilitation of multi-family housing. Tenant selection for these units is restricted to low- and moderate-income families who meet HUD criteria.

A Section 8 Certificate program is available in all states. Through this program a tenant who is eligible for a housing subsidy receives a Section 8 Certificate and then locates a landlord who is willing to accept the Section 8 resident and the approved subsidy. Subsequently the prospective landlord is interviewed and the premises are inspected. In this program the tenants pay 30 percent of their gross income toward rent and utilities.

In some states, a landlord can apply to the Section 8 program for moderate rehabilitation of units in a multi-family home. In exchange for the loan for moderate rehabilitation work, the landlord agrees to accept Section 8 tenants in the rehabilitated units for a period of 15 years.

Other programs which have housing dollars administered by HUD include the HUD 202 program for group living situations and funds from the **McKinney** Homeless Assistance Act. There are still some legal questions being posed as to the eligibility of people with AIDS in **McKinney** and Section 202 programs. Additionally, some states may have programs specifically for the disabled, which may include people with AIDS. For example, Massachusetts administers the "689 Program" for the development of special needs housing and "**667/705** Programs" which provide handicapped units within public housing. These programs are not always open to people with AIDS and often have long waiting lists.

Eligibility of people living with HIV/AIDS for federal housing programs for the handicapped was discussed at the March 1992 hearing of the National AIDS Commission in Boston, Massachusetts. In the report of the National AIDS Commission the Commissioners recommended that "Congress mandate that HUD recognize HIV/AIDS as a disability and not continue to deny people with HIV/AIDS access to housing funds targeted toward the disabled."⁶

HOUSING ASSISTANCE PROGRAMS - DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

TABLE3

CATEGORIES	PROGRAMS	TARGETED POPULATIONS
<p>AIDS Specific Funding:</p> <p><u>AIDS Housing Opportunity Act</u></p> <p>AIDS housing information; short term housing, services and rental assistance; housing assistance and community residences and services</p>	<p>◦Housing Opportunities for Persons with AIDS (HOPWA)</p>	<p>People with AIDS</p>
<p>General Funding Available to PWAs & Others</p> <p><u>Housing and Supported Services</u></p> <p>Rental assistance with supportive services and a matching requirement for funds</p>	<p>◦Section 8 Moderate Rehabilitation Program for Single Room Occupancy Dwellings</p> <p>◦Sponsor-based Rental Assistance</p> <p>◦Tenant-based Rental Assistance</p>	<p>Homeless persons who have a severe mental illness, chronic alcohol and/or other drug abuse problems or AIDS</p>
<p><u>Rental Assistance</u></p> <p>Provides for designated rent with co-payment of 30% of adjusted gross income of client</p>	<p>◦Section 8 Certificate Program</p> <p>◦Single Room Occupancy Section 8</p> <p>◦Project-based Rental Assistance</p>	<p>Homeless and Income Eligible</p>
<p><u>Capital Grants/Loans</u></p> <p>Acquisition, new construction or rehabilitation of projects</p>	<p>6 Rental Rehab Program</p> <p>◦McKinney Transitional Housing Demonstration</p> <p>◦McKinney Permanent Housing for the Handicapped Homeless</p> <p>◦McKinney Emergency Shelter Grants</p> <p>◦Section 202/811 Program</p>	<p>Homeless</p>
<p><u>Operating Cost Assistance</u></p> <p>Costs of operating and maintaining developments</p>	<p>◦McKinney Transitional Housing Demonstration</p> <p>◦McKinney Permanent Housing for the Handicapped Homeless</p> <p>◦McKinney Emergency Shelter Grants</p>	<p>Homeless</p>

The HUD program focusing on HIV/AIDS housing is called the "Housing Opportunities for Persons With AIDS Act" (HOPWA). For this program, which was not in place during the period of study, 50 million dollars was appropriated in 1992; 90 percent of these dollars will be allocated to states on the basis of AIDS incidence and 10 percent will be competitively allocated to meet housing needs in states that do not qualify under previous requirements. Projects funded by the HOPWA include: housing information services (counseling, information and referral); AIDS short term supported housing and services; short term rental assistance; single room occupancy dwellings development; and community residences and services.

The Shelter Plus Care Program is another HUD initiative to provide permanent, supportive housing for homeless persons who have severe mental illness, chronic alcohol and/or other drug abuse problems, or HIV/AIDS. One-hundred-and-ten million dollars was appropriated for this project in 1992. It allows a variety of housing choices with a range of supportive services to respond to the needs of a difficult to serve homeless population. The three components of the program are: Section 8 Moderate Rehabilitation Program for Single Room Occupancy Dwellings; Sponsor-based Rental Assistance; and a Tenant-based Rental assistance which was not funded in the 1992 fiscal year.

While there are a variety of housing programs that provide funding for developing and operating residential services for people with HIV/AIDS, this research has revealed some access barriers that have proved formidable for HIV/AIDS housing/service providers. The primary issues for service providers seeking funds is the gap in knowledge and experience between those applying for funds and those providing funds. In the field of AIDS/HIV housing, most of the housing providers come from the AIDS service delivery field and are relatively naive about housing development language and procedures. The funders, on the other hand, are sophisticated housing developers and residential managers.

The gap creates a barrier for those seeking funds because they may be intimidated by the application process, or may misunderstand requirements or be unable to meet them with their current resources. For example, prior to the HOPWA and Shelter Plus Care Programs, a I-IUD program application required architectural plans, which is daunting to an AIDS service organization with little, if any, experience in architectural expertise. A melding of the skills of service providers and housing developers is necessary in order to overcome the barriers that exist in providing supported housing to people with HIV/AIDS.

E. Occupancy Levels

A few previous studies^{7,8,9} have documented the need for housing services for persons with HIV/AIDS. The continuing need is anecdotally reinforced by this study. Residential services for people with HIV disease are by and large **all** at capacity, many with waiting lists. Those that are not at capacity are generally facilities that are very structured and place extensive restrictions on residents relative to their level of independence. Underutilization has also occurred when needs were not accurately predicted, as is the case in some hospices, where the issue of how AIDS care fits with the hospice philosophy has made the setting less desirable for people with this disease.

Some communities have been able to manage the differing occupancy rates of their available housing options by creating housing clearinghouse/referral centers. The Northwest AIDS Foundation in Seattle, Washington, for example, collects information on all AIDS-appropriate housing units, houses, or beds and makes referrals to individuals seeking housing of what is available and appropriate to their needs. Seattle is also unique in offering a complete continuum of housing options including shelters, scattered site apartments, several congregate homes, ALFs and an HIV-dedicated SNF (soon to be completed). Such organization allows for some transfer of demand across housing types, based on the current supply, as well as assisting individuals in making transitions from one type of residence to another as their disease progresses and housing needs change.

One lesson that can be drawn from providers' experience with occupancy rates is that residential services must remain flexible in format because of the impact individual preferences have on demand. That is, persons with AIDS have been seen to have strong preferences about their housing which are reflected in the acute demand for certain settings and disregard for others. However, there has been little research in the housing needs and desires of persons with HIV/AIDS. Planners should be aware of the importance of preferences of people with HIV/AIDS, and, at the same time, of the lack of data available with which to plan.

F. Provision of Health Care and Social Services

Each type of housing situation provides a different array of services depending on the level of assistance required by the residents. In more independent living arrangements, such as scattered site apartments or congregate homes, services are often coordinated by the AIDS service organization or city agency that is sponsoring the housing. In these facilities, residents are encouraged to use such services as buddies, support groups, referrals for in home medical services and assistance, etc. Often clients arrange their own services and maintain ties with service providers independently, but stay within the service organization's network. On site support staff in intermediate level housing (i.e., congregate and some ALFs) often provide assistance in scheduling, meals, housekeeping, house administration, and getting transportation to medical services off-site. In the higher level settings, more care is usually provided on site, either by on-site staff or through contracts with health care agencies (often the house/agency contracts with a home nursing agency, for example, to provide services for all residents, rather than each resident making individual arrangements).

How much care to provide and the mechanisms for obtaining funding or reimbursement for these services are considerable challenges for housing providers. At a minimum, residential services must be located in reasonable proximity to medical facilities in order to provide residents with access to their care providers (walking distance is preferred, although close proximity to direct bus routes is acceptable). The variety of service arrangements across and within housing types is evidence of the difficulty in devising and funding health and social services within a residential service setting, as well as the strong need for such services by persons with HIV or AIDS living in these residences. It also indicates the need for collaboration between housing providers and health providers.

G. Resident Issues

As a whole, residents who choose to use the facilities described in this report are very satisfied with their choice. However, this satisfaction must be considered with the a significant caveat: We do not have any information on people who are not satisfied with their housing situation. Residents are all self-selected into the different housing models.

Because of the diversity of the HIV-affected population, however, issues of integration of lifestyles and preferences have arisen. Most assisted living or **skilled** nursing facilities integrated male, female, gay and heterosexual populations, as **well** as substance abusers in recovery. Those that included a measure of individual choice in housemate selection (congregate homes) tended to be composed of primarily gay men.

Many residents in congregate facilities are pleased with the availability of home health support services as well as mental health support in their housing situation. They also articulate a comfort level in living with others who have AIDS. Residents and staff often acknowledge that not all people are suited to life in congregate living situations. At the same time, many residents feel that these types of housing situations allow them additional personal spending money from their SSI benefit since their rents are usually subsidized.

The close proximity of fellow residents in some living arrangements has brought up the need for adequate methods to deal with addictive personalities, behavior associated with dementia, and acting out/violence. Leases or individual contracts are often used to ensure compliance with house rules and regulations. Administrative staff have been able to use the leases or contracts as one way of communicating rules and an outlet for evicting the resident if problems arise. Generally, belligerent residents with active substance abuse problems who exhibit acting out behavior are asked to leave after sufficient warning, and options for treatment in a substance abuse program are offered.

Because each type of residential setting provides different services and has different requirements of its residents, individuals tend to self-select the type of situation that is most appropriate. People with AIDS need the choice of a full spectrum of housing options to adequately meet their housing needs.

H. Community Acceptance

Despite many fears about community resistance to HIV-specific residential services, community acceptance has not been a significant problem for housing providers. Although individual projects have experienced battles, some more serious than others, on the whole, residences have not been prevented from opening because of community opposition, nor have they experienced serious problems thereafter. Literature related to mentally ill and mentally retarded populations cite several positive characteristics associated with potential tenants. These include: self sufficiency, ability to pay the rent, ability to maintain the property, and ability to obtain supervision from families or agencies.¹⁰ In general HIV/AIDS tenants possess these characteristics (especially if there is agency or financial support) which may in part explain the relative lack of resistance observed.

At the same time, these residences are usually located in either gay neighborhoods where there is support from the community, in poorer neighborhoods where organized resistance to development is rarely a factor, or in areas where group homes and other ~~non-~~residential use is already present and neighbors do not perceive a personal threat. There may be some planned avoidance of neighborhoods where community opposition would be a barrier, but at this point, residences are being built and operated despite any opposition that may exist. However, most housing options are currently in areas of the country where HIV and AIDS are familiar conditions. As the disease spreads to rural areas and services follow, the fear level (and thus opposition) might be stronger.

It should be noted that this general community acceptance of residences has not come without work. Project developers, as a group, have done extensive strategizing to avoid opposition, whether that has meant personally canvassing **all** neighbors or specifically avoiding any kind of publicity. Community acceptance is a significant factor that is considered in the development process, but to date it has been a manageable factor.

IV. RESULTS/SUMMARY OF FINDINGS

Housing is one of the newer additions to the array of services provided to people with HIV/AIDS. In recent years it has become clear that people with HIV/AIDS have specific housing needs as a result of their illness, and a variety of attempts have been made to assess and address these needs.** The result is a spectrum of housing alternatives, some more developed than others, that attempt to meet needs at different stages of the disease, with varying levels of success. The outcomes of these efforts are reflective of both the efforts of those in the AIDS housing field and the overall housing field on its own. A recent Massachusetts Department of Public Health request for proposals summarized the goals of housing programs for people with HIV/AIDS.* These goals include:

- o facilities which operate to the greatest extent as a home and not an institution, allowing the **occupant** to have maximum control over his/her privacy, living space and behavior;
- o residences located in areas of greatest need and prevalence of HIV/AIDS;
- o residences integrated into communities accessible to families and friends, medical centers and public transportation;
- o residences which combine all available and appropriate sources of funding including Section 8 rental subsidies and existing housing based assistance;
- o supportive residential facilities to provide pediatric respite for families of children with HIV;
- o alcohol/drug free housing in conjunction with services to single men, women, and women with children in recovery from substance abuse;

- o expansion of skilled and intermediate nursing beds to accommodate residents who are not geriatric but diagnosed with HIV;

- o congregate housing for those who require some level of supervision yet require support of community setting.

The following section discusses our major findings in the design, development, and operation of residential services for people with HIV/AIDS.

A. **Impact** of Housing on Disease

People with HIV and AIDS have a continuing need for medical care that increases as their disease progresses. As is true for all homeless persons, it is difficult, if not impossible, to maintain regular medical care without stable housing. Such care is imperative to persons with HIV or AIDS in order to manage their disease and keep progression as slow as possible. Thus, without adequate housing, HIV and AIDS are exacerbated.

We have seen that when appropriate housing is provided, people with HIV/AIDS tend to improve medically. The reason for this improvement can only be speculated, but may include reduction in stress, better access to medical care, improved support services, or better emotional status from the support of co-residents or staff. Whatever the reason, it is clear that housing has an impact on medical status and thus should be considered as an element in a person with HIV or AIDS' treatment plan.

B. AIDS Service Community Response to Housing Need

As AIDS activists and others became aware of the need for residential services for people with HIV/AIDS, their response was to design housing options to meet the perceived needs in their community. These responses were generally developed without any data on needs and without the help of a formal needs assessment process. Current programs have become aware of their previous misconceptions about housing needs and preferences and have had to make adjustments in their facilities or populations served, or struggle with the consequences of their informal planning processes.

There was little coordination across communities, much less with other providers of residences nearby or in other areas. In addition, these organizers were almost uniformly ignorant about housing design or development at the start of their endeavors and tended to "learn on the job." They are typically people with political, health care or religious backgrounds, and little housing experience. At the same time, existing providers of residential services lack knowledge about HIV disease and the needs of people affected by the disease. There is a strong need for coordination among providers in order to facilitate sharing of information, as well as training in both housing and HIV/AIDS needs for all involved.

C. Financing Strategies for Residential Services

Reimbursement and funding strategies were particularly problematic for providers of residential services. Securing operating funds is a challenge for all providers, as evidenced

by the small percentage of budgets that have historically been funded through rental payments (on average about 30 percent, but ranging from less than 30 up to **90** percent). In theory, residential services should be largely funded through rents as opposed to reimbursements for on-site services.

The availability (although limited) of rental subsidy programs, such as Section 8 housing certificates, should be clearly articulated to all providers, as well as their applicability to congregate and other group living situations in some cases. There is a myriad of federal funding sources through the **McKinney** Act and HUD that can be **used** for development and operations. However, because of the variety of sponsoring agencies as well as limitations and restrictions on most funding, providers are often unaware of the availability of funds or are intimidated by the application process. There is an immediate need for information on the availability of funding and training in the application processes. To the extent possible, regulations and requests for proposals should be articulated for the housing lay person to accommodate those working in this field.

Passage of the Ryan White Care Act had little impact on housing services provided through the HRSA service demonstration projects because these projects were not relying extensively on federal funding for housing at the time of passage. **Earlier** funding policies reduced the demand on federal funding for housing services. Some support services provided in the residential settings had been funded with federal dollars in the past and continued to be funded with the passage of Ryan White. In general, however, neither Ryan White nor other federal sources provide adequate funding for housing services.

Many providers are unwisely relying on fundraising efforts to maintain their operating budgets. Fundraising dollars are unpredictable and, in general, should not be relied upon for operational expenses. Assisted living facilities in particular exhibit this overreliance. Fundraising efforts are also labor intensive, and programs sacrifice staff time that could be used for services or funding that could be put toward additional space or beds for the sake of continuous fundraising. Training in financial management and reimbursement strategies would be valuable to these providers and would complement the above-mentioned information on government programs. As a health-focused agency, HRSA is not necessarily the appropriate source of this provider assistance. Nevertheless, HRSA could offer an impetus for the provision of training from another source.

Pediatric residences should be noted as the exception to this discussion. They have been very successful at major corporate fundraising with a reasonable level of effort compared to that expended by the adult-focused programs. Their success indicates that, at least for the moment, their course is appropriate.

D. Resident Concerns

In almost all cases, confidentiality is sacrificed through the provision of residential services. The lack of confidentiality has been accepted by both residents **and** providers because of the overwhelming need for housing. In the future, however, as options increase and models are refined, it would be wise to consider methods to ensure this right as it is ensured in other areas such as health care. Because no one has been successful on this front,

there are no models to follow. The issue of segregated "AIDS" facilities versus, apartments or homes integrated into the community has been debated but there is no consensus on merits or drawbacks. A distinct model violates confidentiality for all residents, yet also provides a high level of support because of the accessibility of neighbors with similar life circumstances. Our findings in this area are inconclusive, but the importance of the topic is clear.

Integration of different populations can also be a problem. People who are mentally ill and have HIV often go unserved because they are not integrated into the non-mentally ill residences nor are they well-served in the non-HIV settings for persons with mental illness. Substance abusers who are actively using drugs or alcohol are also overlooked by many residences because of prohibitions on substance use in most settings. The **crucial** factor in guaranteeing successful integration of different populations seems to be the role of the provider in acting as intermediary. The provider must be prepared and available to mediate between residents, as well as between residents and neighbors; it is clear that simply providing a shelter space is insufficient. People with HIV/AIDS clearly benefit from sharing living space with others, and facilitating this situation through mediation, support, or other means ensures benefits without problems.

In addition, there is a lack of residential services for women with HIV/AIDS and particularly for families. This situation is likely the result of the original direction of the epidemic, as well as the focus of many of the groups originally involved in developing housing options, but should not continue in the future. Women and families are in dire need of appropriate housing, yet there is little information on their specific needs and options. HRSA should consider sponsoring additional research into these needs, or create incentives (perhaps in coordination with HUD) to design and develop services for women and families.

E. Implementation of Housing Programs

The lesson learned from the experiences of providers to date is that housing models must be designed for and responsive to the community at hand. A militant, litigious approach may be appropriate in a particularly hostile community, while a deliberate, informative, personal campaign to win support and acceptance may work better in a community that is accepting in principle, but has reservations in practice. Sharing of information across projects is important in this area because of the variety of approaches available for consideration for each situation. The important point to remember is that an individual plan must be designed for each situation to address the particular needs of the community, and each plan should be flexible enough to respond to changes in the population, the course of the disease, and/or the preferences of those being housed. In addition, this population needs a continuum of housing options to meet the range of needs as the disease progresses, and some coordination of the available options is useful in accessing services, minimizing overlap, and maintaining high occupancy levels.

In general, our research has shown that housing for people with HIV/AIDS is still in its infancy, with models being developed and tested, adapted and modified as lessons are learned. At the same time, the nature of the HIV is that life spans, condition, treatment regimens, and other aspects of the disease are constantly changing, creating an environment that requires **flexibility** among providers in order to effectively respond to needs. In addition,

the general lack of affordable housing in many communities has affected the provision of housing options for people with AIDS as it has affected all persons. People with HIV and AIDS have the problem compounded by their medical and social needs. Providers of residential services must develop strategies that address the specific needs of people with HIV/AIDS, as well as take into consideration the general housing situation in their communities in order to be successful. This challenge indicates the need for information sharing as well as training in the areas noted above. These two mechanisms would have a significant impact on the quality of services provided, which is linked to the quality of life and medical condition of persons living with HIV/AIDS.

REFERENCES

1. Housing and the HIV/AIDS Epidemications for Action, National Commission on AIDS, Proceedings of March 1992.
2. Nagy, Michael. (1989). Decongregating a residential program for people with psychiatric disabilities. Psychosocial Rehabilitation Journal, **12**, 70-74.
3. Blanch, Andrea, **Carling**, P., Ridgeway, P. (1988). Normal housing with specialized supports: a psychiatric rehabilitation approach to living in the community. Rehabilitation Psychology, **33**, 47-55.
4. **Margolis**, Jerome, Charitonidis, T., (1981). Public reactions to housing for the mentally retarded. Exceptional Children, **48**, (1), 68-70.
5. **Hummel**, R., Wells, D., Rodriguez, G., Femandez-Rubio, H., Rotkiewicz, L., Jackson, J., (1990). Survey of emergency housing facilities in New Jersey for people with AIDS and HIV related conditions. (From Sixth International Conference on AIDS, June 1990, Abstract No. E.707)
6. Housing and the HIV/AIDS Epidemic: Recommendations for Action, National Commission on AIDS, Proceedings of **March 1992**.
7. **Howell**, EM., **Andrews**, R., **McClung**, R., Preston, B., Keyes, M., (1990). Community Response to the AIDS epidemic in four US cities: New York, San Francisco, Los Angeles and Miami. (From Sixth International Conference on AIDS, June, 1990, Abstract No. W.E.P. 70)
8. Sherer, R., (1990, June 20-23). The future of AIDS services at Cook County Hospital, Chicago. (From Sixth International Conference on AIDS, 1990, Abstract No. 4019).
9. Stanton, D.L. Smith, M., **Rucker**, S., **Chaisson**, R., Hidalgo, J., Fine, E., Bartlett, J., (1990) A regional center for early medical and psychosocial assessment of HIV infected persons. (From Sixth International Conference on AIDS, 1990, Abstract No. **S.D.** 832)
10. **Salend**, Spencer J., Michael, Robert, Veraja, M., **Noto**, J., (1983). Landlords' perceptions of retarded individuals as tenants. Education and Training of the Mentally Retarded, **18** (3), 232-234.
11. Beresford, Larry. (1989, January). Alternative outpatient settings of care for people with AIDS. ORB, **15**, 9-16.

12. **O'Keefe, S. W. (Ed.).** (1990, May). Request for proposals for residential services for adults, families, and people in recovery from substance abuse who are affected by AIDS and HIV infection (Available from the Massachusetts Department of Public Health/AIDS Bureau)

Home Care Services for Persons with HIV Illness

Analytic Synopsis

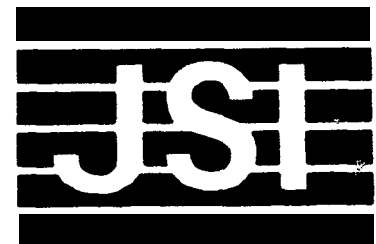
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JOHN SNOW, INC.

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HOME CARE SERVICES FOR PERSONS WITH HIV ILLNESS.

Executive Summary

Home health agencies play an essential role in the delivery of care to persons with HIV illness. Characteristics of the populations initially affected by HIV (young adults living apart from traditional families) and the episodic nature of the illness itself have contributed to the demand for skilled nursing and other support services in the home. However, there has been little published research concerning the extent, process or outcomes of HIV home care during the first decade of the epidemic.

This report summarizes the findings of a study conducted in **1991** by researchers at John Snow, Inc. (JSI) with support from the Division of Health Resources Development, Division of HIV Services, Health Resources and Services Administration (HRSA), U.S. Public Health Service. The project was an analytic synopsis of the current status of home care services for clients with HIV illness. Goals of the study were to identify and analyze exemplary programs and elucidate the organizational, financial and operational issues affecting access to and delivery of home care services.

The researchers conducted an extensive literature review, followed by qualitative field research in two parts:

- 1) In-depth site visits to four cities (Boston, Dallas, Denver, Jersey City) representing the spectrum of regional variations in HIV epidemiology. These sites were selected because they had well-established HIV home care programs within a network of care supported by **HRSA's** original HIV Service Demonstration Projects.
- 2) Key informant interviews with representatives of other leading programs and other recognized experts in the field.

Summary of Findings

Advantages: Home care for patients with HIV illness has important advantages over hospital or institutional care, including:

- flexibility --- the care plan and services can be easily modified as changes in illness and acuity level require;
- patient satisfaction --- in a familiar, safe and nurturing environment, with family and other supports nearby, patients generally have improved quality of life;
- **cost** --- the level of home care required for most patients falls well below the cost of acute hospitalization. However, at moderate to high acuity levels, comparisons to other forms of institutional care are not necessarily favorable.

Services: At the study sites, the standard services provided for clients with **HIV** included skilled nursing care and intravenous infusions (of both approved and experimental

medications), home health aide services for personal care assistance, and homemakers for light housekeeping tasks.

Beyond these basic services, however, the sites had demonstrated vision and creativity by developing new services and approaches in response to unmet client needs. Among these program enhancements were: a) transportation to clinic appointments provided by home health aides in a site where public transportation is limited; b) “drop-in” nursing coverage at a day care program for adults with HIV to monitor clinical status and oversee medication administration; c) respite and training programs for informal caregivers, using volunteers of a local AIDS service organization and paid staff; d) specialized mental health consultation for clients and bereavement counseling for loved ones; e) family-centered model of care for families with multiple generations and individuals infected; **f)** terminal care and death pronouncement by registered nurses (where legally feasible) so that patients can die peacefully at home.

Organization: Study sites demonstrated the successful use of both specialized and integrated organizational structures for their HIV program. The specialized programs were organized according to specific grants (e.g. HRSA Demonstration Project) or funding sources (e.g. Medicaid waiver programs) and patient services were dictated by the grant’s reimbursement criteria. Productivity standards for specialized HIV nurses were reduced **27-44%** compared to generalist nurses (i.e. 19 vs. 26 visits per week for full-time nurses). To reduce turnover and staff “burnout” several sites had plans to upgrade the HIV specialist positions within their organizational and salary structure.

The larger agencies used an integrated approach, whereby a **small** core team of HIV specialists or case managers coordinated the more complex cases. **All** agency staff received HIV training and were expected to care for the clients with HIV residing in their assigned catchment area. The core specialty team or HIV coordinator consulted with the generalists and informed them of resources available outside the agency through **local** service networks.

Staffing: Professional staff were required to accept **all** patient assignments, and few recruitment or retention problems were reported at the study sites. Ongoing staff support groups were in place at most sites and thought to be an important buffer for the stress of caring for young clients with terminal illness. Nurses were often frustrated by the complicated reimbursement rules and additional paperwork involved in the HIV programs; these factors contributed to the staff turnover.

Paraprofessional staff (e.g. homemakers and home health aides) were intermittently difficult to recruit and retain. Concerns of occupational risk posed by their family members were a major obstacle. Specialized training and recruitment strategies (e.g. through local gay press and organizations) were successful in overcoming initial personnel shortages. One agency offered a salary differential (**\$0.25/hour**) for working with HIV-infected clients, but this was in accordance with an established precedent for “high intensity” cases. Other incentives used included the opportunity for more hours and cases when desired, and programs to educate family members about the established low occupational risk and routine precautions.

Overall, approximately 80% of direct care in the home is provided by informal caregivers such as family, partners, and friends. These individuals always need support, training and respite options, but there is limited availability of such services. Home care agencies are ideally suited to develop and provide them. In rural areas, volunteer services are the key to keeping patients out of the hospital during episodic periods of illness. Informal caregivers play such a critical role that modest reimbursement to them could be a cost-effective use of public funding in cases where their financial needs jeopardize their ability to continue supervision of care. The availability of an informal caregiver can be the difference between low-cost home care and expensive institutional alternatives.

Difficulties: Despite their many achievements, home care agencies currently face major structural, institutional and financial obstacles to providing high quality HIV services. Three examples of significant issues are described below:

- **Home care service plans at the study sites were driven by the available reimbursement rather than the client needs.**

For example, a psychiatric clinical nurse specialist was part of only one program, the site where local Medicaid benefits covered her services. All other sites viewed mental health support as a critical aspect of patient needs and an essential safeguard for preventing staff burnout.

- **Agencies serving many clients with HIV encounter financial difficulties because skilled nursing visits are reimbursed at a flat rate, regardless of length.**

This is--a significant problem in agencies serving a high proportion of HIV clients because HIV-related visits are 29-100% longer than other home care visits, due to the complex medical, social and emotional needs of the clients. The agency receives the same reimbursement (approximately \$60) for a 15 minute blood pressure check as for a 3 hour infusion visit to a debilitated client with HIV. In states where Medicaid policies base payment on "class rates", agencies disproportionately involved in HIV care (compared to their competitors) suffer financially because rates are set on typical experience of the class of agencies, and would tend to be artificially low.

- **As eligibility for Medicare coverage becomes more commonplace among clients with HIV illness, new financial difficulties will emerge.**

With improved treatment, more HIV-infected patients are surviving the 29 month period of disability necessary to qualify for Medicare. Currently, Medicare home care benefits require patients to be "homebound" and in need of intermittent skilled nursing care. This is not necessarily the case for clients with HIV whose clinical illness waxes and wanes and is punctuated by periods of improved functioning when IV medications and other assistance may not be needed. Also, Medicare provides limited periods of coverage and restrictive reimbursement for IV infusions that does not include the cost of the medication. In HIV therapy, expensive antiviral drugs (e.g. foscarnet and ganciclovir) are commonly used lifelong; the cost associated with these medications will be beyond the means of the majority of patients and could quickly outstrip the budgets of public medication reimbursement programs

(such as those **supported** under Title II of the Ryan White CARE Act) if they are viewed as the alternative funding source.

Significance: The benefits of assuring widespread availability of appropriate and flexible home care services, which have been previously documented for elderly clients (i.e. cost savings compared to in-patient care, patient satisfaction and improved outcomes) appear to be shared by clients with HIV illness. At each level of this study, we found home health care to be an essential element of comprehensive service networks for persons with HIV illness; clinical trends suggest that they will become increasingly important in the future. Home care agencies **have** untapped potential to fill service gaps and respond creatively to client and community needs. Our findings support the continuation of federal funding for HIV home care with expansion of the scope of services and reassessment of eligibility criteria and reimbursement guidelines so that the unique needs of HIV clients can be taken into account.

HOME CARE SERVICES FOR PERSONS WITH HIV ILLNESS

Analytic Synopsis

I. OVERVIEW

This report represents the completion of a study focusing on the development and current operation of home care services for persons with HIV disease. The information upon which this analytic synopsis is based includes:

1) Extensive review of the literature: We conducted a review of all relevant literature, including current articles specific to HIV home care and earlier publications that described and **analyzed** important aspects of home care programs for the elderly. Because the field of HIV home care is relatively recent and has been rapidly developing, the most useful literature has been found outside of the traditional medical and nursing literature. Reports found in the proceedings of recent conferences have been most timely and comprehensive. The background provided by articles that deal with earlier evaluations of community-based care demonstrations targeting the **frail** elderly has been extremely enlightening and serves as a framework for future research in HIV programs.

2) In-depth site visits to leading HIV home care agencies: Four programs were visited (Boston, Dallas, Denver, Jersey City) between **August** and October 1991; **all** sites had been participants in HRSA-funded HIV Service Demonstration Programs, and were selected because they successfully developed and sustained comprehensive programs to provide various in-home services for patients with HIV. Taken together, the four sites represented a diverse patient population and illustrated various approaches to program organization. The agencies ranged in size from 160,000 to 680,000 visits per year and served between 220 and 800 HIV patients **annually**. The smallest agency served the most HIV clients; 40% of their 1990 visits were to clients with HIV-related primary diagnoses.

3) Telephone interviews with key individuals in the field: Additional data was obtained through a series of detailed telephone interviews with representatives of other HIV home care programs from cities not included in the site visits. These included New York City, Seattle, Baltimore and Columbus, OH. Background on several research studies in progress, which will be very informative to future program plans, was obtained in this manner. This complementary information has served to provide a more well-rounded basis for the analytic synopsis that follows.

This paper has been organized to reflect the research questions that guided this study. They begin in Section II with general background material describing the issues of funding and structure. A specific description of current HIV home care services and their place in the continuum of care follows. The roles and issues facing formal and informal caregivers are

discussed in **detail** in Section IV, followed by descriptions of various target populations and attempts to monitor service utilization. In section VI, program outcomes and the approaches to case management and special populations are reviewed. Various institutional alternatives to care in-home are discussed next, and followed by considerations for policy makers and future service and research issues.

II. ORGANIZATION AND FINANCING

A. Essential Components of Community-based Service Network

To fully appreciate the important role played by home care agencies serving clients with HIV illness, a broader perspective on the components of the community-based service network and the full range of services that may be required throughout the course of illness is necessary. In the early stages of HIV disease, needs include primary medical care for clinical monitoring, **legal** assistance, mental health programs, advocacy, education and treatment information. During acute illness, hospital care followed by outpatient and/or **rehabilitation** therapy are needed; home care services typically begin following an acute hospitalization.

As the illness becomes more chronic, the service needs are increasingly diverse: personal care, practical support, light housekeeping assistance, home-delivered meals, transportation services, adult day health care or social day care, congregate housing or **assisted-living** facilities. Home care services, both **skilled** nursing and paraprofessional (home **health** aide or homemaker), are often the cornerstone of the plan of care.

The skilled nursing services frequently include intravenous infusions of antivirals (for cytomegalovirus infection), antibiotics (for disseminated mycobacterial infection) or parenteral nutrition (for wasting and cachexia). While there is currently one infusion treatment that is short term (amphotericin for cryptococcal meningitis), all other infusions are required lifelong, and permanent IV catheters for long term access are needed. Usually, patients and their informal caregivers are taught to administer the medications and change dressings and IV line supplies. At the terminal phase of illness, hospice services and bereavement services to family and friends are needed.

Case management, though variously defined and organized, has become a necessity in HIV disease for many reasons. The average consumer finds understanding our complicated system of agencies and entitlements difficult, and needs specialized assistance in order to negotiate the complex service network. Certain features of the illness itself have intensified the **reliance** on case management: clients typically are young, often disadvantaged financially, and lacking traditional family supports. The consequences of HIV infection include a spectrum of problems -- medical (ie. infections, cancers, general progressive debilitation, blindness), mental health (ie. dementia and substance abuse), and social (ie. need for housing and income maintenance). These issues can only be solved with assistance from agencies and institutions representing various disciplines. A specially trained case manager who constantly keeps abreast of the key elements in the service network can best address the needs of a person with HIV.

B. Home Care Cost-effectiveness vs. Acute and Chronic Care Facilities

It is widely accepted that the provision of long-term care at home represents the least restrictive environment for the chronically ill patient'. There are benefits in the areas of patient satisfaction, responsiveness to treatment and mental health outcomes that result from the familiar, safe and nurturing environment of one's own home. The alternatives of institutionalization (ranging from skilled nursing facilities, supervised residences, group homes and acute-care hospitals) result in various degrees of intrusion, disruption, and loss of **self-determination**; for these reasons, patients generally view them negatively compared to the option of staying at home.

The appropriateness of home or institutional care is also influenced by the illness characteristics. Admission criteria for long term care institutions are set to maximize their cost-effective use, but are most appropriately applied to patients with stable and predictable chronic illness patterns, and constant needs for assistance with activities of daily living (so called "**ADL's**") and personal care. The variable and unpredictable course of HIV illness makes long-term institutional care difficult in most cases. HIV home care providers report that clients experience frequent changes in the acuity level of their care. **While** repeated episodes of infections lead to temporary intervals of increased care needs, patients generally respond to treatments with marked improvement in their level of functioning. Care plans are continuously revised and services adjusted to meet these fluctuating needs. Such adjustments are difficult within skilled nursing facilities and other levels of long term institutional care. Therefore, home care has come to be viewed as the uniquely appropriate setting for long term care of most clients with HIV.

Before HIV became an issue for health services research, studies to evaluate the financial impact of home and community-based services for the elderly yielded inconclusive and conflicting results. It is no surprise then that there are lingering questions about the **cost-effectiveness** of home care in HIV illness. The answers depend on the particular institutional alternative (acute hospital, nursing home, etc.) that is used for cost comparisons.

From the mid-1960's through the mid-1980's, over 150 reports have been written that attempt to quantify the benefits of home care for the elderly. The more recent of these **also** assess costs compared to institutional alternatives. Weissert and colleagues summarized the 27 most rigorous and generalizable studies*, according to the following criteria: they primarily served an elderly population, tested effects of a home- and community-based alternative. **to** existing long-term care services using an experimental design, and included at least **50** individuals in the treatment and control groups. The findings are discussed **below**.

Compared to Hospital Use and Expenditures

Studies in the elderly found high rates of admission and long hospital stays in the elderly "controls", enough to produce a potential net savings in many studies. However, admissions were increased in nearly half the studies, and total inpatient days have gone down in some studies but up in others. Very few reports provided the data necessary to calculate per diem costs; 50% (**3 of 6**) indicated slightly lower per diem expenses for the **group** receiving home- and community-based services.

Subgroup analyses revealed significantly lower hospital use among treatment group members who: a) were not severely disabled, 2) had a good prognosis, 3) had moderate unmet needs, and 4) were at high risk of institutionalization. Significantly higher hospital use was consistently demonstrated for home care clients with a poor prognosis who were extremely impaired in **ADL's**. Therefore, the suggestion is that targeting home and community care services to patients with only moderate needs, good prognosis and the support of others might result in cost savings through reduced hospital use.

Compared to Nursing Home Use and Expenditures

The major difficulty encountered by the demonstration projects of home- and community-based care for the elderly is that the nursing home utilization in the control group was surprisingly low---less than 25% in most studies. The per capita annual nursing home expenses were below \$2100 in 2/3 of the studies. Consequently, there is very little potential for offsetting home care costs.

However, there have been demonstrations that succeeded in reducing nursing home utilization. The key factor was the ability of the program to target the patients most likely to enter a nursing home. Future studies should use multivariate analysis to identify and define subgroups based on their risk of institutionalization.

Despite the widespread attention to this issue, there has been rather limited improvement over time within this field of research. Perhaps this can be explained by yet another dynamic--the reduction of nursing home use is a moving target. Nursing home bed shortages and escalating costs, coupled with preadmission screening programs, have made those actually at risk of--entry a smaller and much sicker group. Therefore, the community care programs have difficulty finding an adequate sample of high-risk patients within their service area.

Comparing the Elderly to the Patient with HIV Illness

Many of the difficulties with establishing clear cost-effectiveness for geriatric patients are likely to apply to patients with HIV illness when such evaluations are undertaken in the future. However, for now there is a glaring difference between the two patient populations with respect to their options for long-term care. For the elderly, **skilled** nursing facilities are an available and realistic option to remaining at home with assistance. At present, in many locations throughout the United States, there are no skilled nursing facility beds available for HIV clients.

The reasons for this include discrimination and fear of persons with HIV, the contention by nursing home administrators that they lack appropriate means of infection control (ie. private rooms, sterilization facilities, disposable, etc.), and the typically limited access to long term care beds in general. In addition, patients with HIV have resisted being moved to nursing homes where programs are geared to the elderly and staff are **unaccepting** of their disease and lifestyle. Despite the efforts of many states to initiate legal remedies against discrimination and enhanced reimbursement rates to force nursing homes into the HIV care arena, very few facilities are considered to be providing high quality care to **HIV patients**.

The cost-effectiveness comparison of home care to skilled nursing facilities is primarily a hypothetical one at the present time.

HIV Cost Estimates from Sample Sites

The programs we studied provided the following cost-comparison data:

a) Home care services, even at an intensive level of round-the-clock home health aide coverage (at **\$11-18/hour** or **\$264-\$432** per day), are generally cheaper than acute hospitalization where room charges alone are between **\$400-\$1000/day**. However, the “room and board” expenses of being at home (food, rent, utilities, housekeeping) are normally not considered in the analysis. Although, like hospital rates, monthly room and board rates vary considerably from place to place, monthly averages are approximately **\$600-\$900** or **\$20-\$30** per day. Thus, under normal circumstances, even an intensive level of home care can be cost-effective compared to hospitalization.

b) **Nursing** home care at the study sites varied in cost from \$45 to \$112 per day (Medicaid rates). **If such care was available for HIV patients**, it would be comparable in price to:

- 1 skilled nursing visit (\$60) with 28 hours of home health aide assistance per week (net **\$81/day**) or
- 2 skilled nursing visits with 20 hours of home health aide assistance per week (net **\$69/day**).

These levels of home care would be adequate for most seriously ill patients who have an informal caregiver on hand.

c) Home care costs would exceed nursing home rates if the patient needed:

- more than 6 hours per day of home health aide with 1 skilled nursing visit/week (net **> \$112/day**) or
- daily infusion visit by nurse plus home health aide coverage **28** hours per week (net **\$132/day**).

States that offer Medicaid waivers for home and community-based services typically cap expenditures at \$1900 per patient per month; this figure is derived from 65% of Medicaid’s skilled nursing facility reimbursement. The cap amounts to \$63 per day and impairs the patient’s access to the levels of care noted above. The standard has been set to be considerably less than nursing home rates, despite the fact that nursing home beds are generally not available. If left at an equivalent daily rate (**\$97/day**), patients in need of significant support would have the necessary flexibility to accommodate episodes of respite for informal caregivers and periods of increased illness.

C. Financial Limitations and Incentives

One of the major financial issues affecting HIV home care services is that all skilled nursing visits are reimbursed at a **flat** rate, without regard to length or intensity. It has been universally noted, throughout all HIV health services research, that patients with HIV require more time from providers at **all** levels. From the available home care literature come numerous reflections of this:

- A 1987 New York study noted that AIDS patients required 29% more nursing time per visit than the typical home care patient, and 13% more time than terminal cancer patients³;
- Massachusetts statewide agency survey determined that nursing visits to patients with HIV illness took twice as long as other home care visits, with a mean length of 1.3 hours⁴;
- One study site reported that **10-15%** of their 1300 skilled nursing visits to patients with HIV each month are longer than 1.5 hours.

The fact that an agency receives the same reimbursement for a 15 minute routine blood pressure check as for a 2 hour infusion visit to an HIV client will be a major concern for policy decisions and program planning. For staffing purposes, agencies have reduced nursing productivity standards for HIV specialty care (see section IV A: Formal Caregivers). Intensive involvement in HIV services will result in reduced revenues under these conditions.

Another issue stems from the peculiarities of Medicaid reimbursement policies in some states. For example, covered services can be extremely limited and create major obstacles to home care providers attempting to serve HIV patients. In one state we visited, Medicaid did not cover respiratory equipment so clients with HIV could not obtain aerosolized pentamidine in the home or other important supportive treatments. In this state, income eligibility limits are so low that SSI recipients who have any assets cannot qualify for Medicaid. The supplemental funding sources for HIV home care (i.e. state and federal grants/service demonstrations) usually have **strict** eligibility criteria targeting underserved populations, which do not permit combining Medicaid with their reimbursement.

Other states are changing to class rates for Medicaid reimbursement of home care. These rates are based on the experience of groups of agencies, and can penalize any agency within the class that provides much intensive HIV skilled nursing care. In one state we studied, the **skilled** nursing visit rate had been reduced from \$63 to \$60 by this method of calculation and the agency could no longer file for a rate appeal for extended length visits.

One of the home care agencies that participated in the **HIV** service demonstration program complained about the funding arrangements for their activities. They were the only collaborator in the service demonstration that was reimbursed on a per unit/performance basis. Other community-based service providers and case management agencies were given salaries for personnel and not held to a performance standard. This caused perceived unfair pressure

on the home care agency to maintain high caseloads. In addition, difficulties in projecting needs for services sometimes led to underspending that later penalized the agency's funding.

The increased use of intravenous infusion therapy at home has spawned another area of growth in the home care industry. Many new proprietary agencies have been established in the past five years, primarily for the provision of IV therapy and other "high-tech" services. In HIV care, the opportunity created by the widespread use of monthly **nebulized** pentamidine treatments (for Pneumocystis prophylaxis) was a unique inducement to this specialty field. The federally subsidized reimbursement programs set up in each state routinely established a reasonable fee for these treatments, and provided coverage for uninsured and underinsured patients.

The demand for infusion services has recently escalated, with the approval of a second drug to treat CMV infection; infusions are given **daily** and continued for life. Conversely, there is a diminished demand for aerosolized pentamidine, following the results of a comparative trial in which an inexpensive oral drug (**Bactrim**) conferred greater protection against **Pneumocystis**⁵. Recommendations have been updated to include Bactrim as the first choice for patients who have no history of serious drug reactions to sulfa or **trimethoprim**⁶.

Home infusion agencies have targeted the practices of major HIV care providers, often creating highly competitive markets in high prevalence cities. Many of the agencies are national in focus, and some have linked with free-standing clinics, community-based clinical trial groups or HIV case management agencies to better establish themselves and create a higher HIV specialty profile. They target patients with private insurance, and establish contracts with large health maintenance organizations and preferred provider organizations. When linked with the agencies' pharmacy services, there is an opportunity to mark-up the costs of medications and supplies in order to assure generous profits to the agency with modest overhead expense.

In one of our study cities, for example, a major proprietary agency's pharmacy charge for pentamidine is \$480 when the drug costs **\$90-\$130** wholesale. They add \$27 for administration of the treatment, bringing the total monthly charge to \$507. The agency does incur expenses **providing** the related services of dispensing and delivery, which would be covered under the pharmacy charge. They accept a reduced reimbursement of \$180 per month from the state's public HIV medication subsidy program (funded under Ryan White CARE Act) when clients are uninsured or underinsured. However, private insurers pay individually negotiated rates for their clients that fall between the **\$200-\$507** range.

Some of the home infusion companies are not Medicare certified, citing demands for record keeping, documentation and cost accounting that are not considered worthwhile. Most agencies are not full-service home care providers and offer no home health aides or personal care attendants. However, in the course of delivering home infusion therapy, their nurses participate in clinical case management and provide psychosocial support and entitlement assistance. **While** their expertise in the infusion field is a valuable asset to HIV home care, some additional fragmentation of care often occurs or is perceived by the client and family when so many agencies (home health aide, home delivered meals, case manager, etc.) are actively functioning in the home.

D. **Sources of Funding**

Medicare has been the traditional mainstay of funding for home care agencies. Agencies studied here reported between 43%-87% of agency-wide reimbursement came from Medicare, with the highest being in a state where Medicaid benefits are limited and eligibility criteria are strict. However, only 2% of clients with HIV are covered by Medicare'. To qualify for Medicare, individuals under age 65 must first qualify for Social Security Disability Insurance (SSDI), wait five months from the diagnosis of their disabling condition, and then survive a 24 month waiting period; a history of employment is also required.

Until recently, typical survival in HIV disease rarely extended beyond these 29 months of disability. Advances in therapy have led to longer survival, and recently patients with HIV have become Medicare eligible. However, Medicare policies are such that many difficulties will arise for the HIV patient who is receiving home care reimbursed by Medicare. For example, Medicare's policies require patients to be homebound and need skilled nursing or other professional care (speech or physical therapists) at least intermittently. Because they are not meant to substitute for long-term care, Medicare m-home services are covered for limited periods (less than four months on average) and must be renewed at least every 60 days. Coverage of specialty care like intravenous infusions is very narrow, and the cost of medications is not included. This **will** lead to major difficulties, as the high priced drugs like foscarnet and ganciclovir become more frequently used and survival continues to be extended.

As in other areas of HIV health care, Medicaid is the principal source of support for home care clients. While Medicaid pays for 11% of health care costs nationally, early reports indicate that 25% of HIV costs are Medicaid reimbursed; in recent years, this figure is trending upward because of the shifting demographics of HIV **illness**. One of the study sites reported that 80% of their patients with HIV were covered by Medicaid, compared to 45% of their agency-wide reimbursement base. However, while home care coverage has been mandatory for all Medicaid programs since 1971, benefits and eligibility vary significantly from state to state, forcing some agencies to rely on grant funds to **serve** the poor.

Since 1981, states have been permitted to apply for Medicaid waivers that establish home and community-based care alternatives to expensive institutional care. To be approved, states must provide assurance that neither the per capita Medicaid expenditures in the target group nor the aggregate Medicaid program costs will increase*. Under waiver programs, states have been able to provide more comprehensive HIV home care including case management, personal care attendants and homemaker services, adult day care, meals delivery, hospice and respite care, and private duty nursing; two of the four agencies visited for this study had benefit of Medicaid waivers.

Private insurance home care benefits have been modeled after Medicare policies, and this has lead to a restriction of community-based services and a bias in favor of institutional care. At our study sites, 520% of home care patients with HIV illness were covered by private insurance.

Specific funding for HIV programs has been provided by the following sources:

- Robert Wood Johnson Foundation HIV Service Demonstration Grants
- Health Resources and Services Administration (**HRSA**) HIV Service Demonstration Projects
- State and city public health budgets for HIV services
- Federal formula grants for home- and community-based services, provided to states during a one-year period
- Ryan White CARE Act funding, Titles 1 (to top 16 cities) and **2** (to **all** states)

In addition, some agencies have devoted part of their United Way funding and other private donations to serving HIV clients; the amount of support from these private sources is comparatively quite small.

E. Effect on, Quality of Care

The study sites we visited dramatically illustrated the fact that home care service plans are driven almost completely by the available reimbursement. For example, services from a psychiatric nurse were made available only at the study site where those visits were reimbursed by Medicaid. However, **all** members of that agency's HIV team considered the services essential to their ability to provide good care, and to prevent staff burnout. Another agency studied. organized their program according to the grant providing support, and the services given to patients were dictated according to the criteria specified by that grant. The plan of care followed directly from the available funding. Monthly caps per patient were typically \$1900, since publicly funded home care services are being capped at 35% below meager Medicaid reimbursement rates for nursing home care.

The complex patchwork of funding sources, each with its own rules and benefits, has caused considerable frustration and stress on the nurse coordinators charged with administering services. In addition, the reporting requirements for various grants have been inconsistent in content and format, further burdening the clinical staff with paperwork and the financial officers with an unstandardized process. Uniformity in benefits and reporting requirements would be a great benefit to providers and administrators alike.

F. Impact of Ryan White CARE Act Funding

Home care agencies were eligible for support under the Ryan White Comprehensive **AIDS** Resource Emergency (CARE) Act of 1990. Title I provided emergency relief funding to the cities (16 in **1991**) disproportionately affected by the epidemic, to be administered according to the priorities established by a local planning **council**. Eligible services included case management, outpatient and support services, and comprehensive treatment services; a 10% cap was placed on the amount designated for inpatient hospital care.

Three of the four sites visited were Title I cities, and all were receiving continued support from the CARE Act funds. In general, the availability of Title I support occurred just in time to replace the earlier funding from the HRSA Service Demonstration Project grant. There was a generally smooth transition and most patients and staff were unaware that the terms of public funding had changed.

In one site, Title I funds supported an expansion of the nursing case management as well as a new initiative---indigenous “community health workers” to be outstationed at the public hospital’s HIV clinic for outreach and continuity purposes. This approach was designed to improve the services and communication linkages to substance abusing clients and certain ethnic minority groups.

The study site that was not Title I-eligible experienced particular difficulties. They had developed and provided HIV home care services under the Demonstration Project, but were challenged to maintain those services in the face of a 50% federal funding cut overall as the project ended. The availability of Title II funds did not adequately fill the gap, and the required **coalition** formation resulted in new tensions and conflicts from agencies attempting to enter the network. More agencies were competing for fewer dollars, and home care services have barely been level-funded.

III. HIV SERVICES PROVIDED BY HOME CARE AGENCIES

A. Addressing the Continuum of Patient Needs

While program models vary among the agencies we studied, the services consistently provided include:

Skilled nursing care, **including** infusions and aerosolized pentamidine treatments; [experimental medications provided under research protocols are widely **available**]

Home health aide services (personal care);

- Homemaker services (light housekeeping, cooking, **shopping**);

Other services varied by site with decisions on services directly driven by available reimbursement and only **occasionally** by the needs of the clients.

In two of four study sites, mental health counseling was provided at home through the services of psychiatric clinical nurse specialists or M.S.W.-level counselors. These two sites also offered a family-centered orientation of care (i.e. maternal-child services). Predictably, these sites were located in cities where the transmission of HIV infection was influenced by injection drug use and consequently, families were multiply infected; also, financial reimbursement was available for these services under local **Medicaid** regulations. Terminal care including death pronouncement by **RNs** was provided by two of the study sites where state regulations permitted a non-physician to certify death.

Certified home hospice services were provided by two of four sites; the other two agencies offered many of the component services encompassed by home hospice but were not Medicare-certified providers. One agency administrator remarked that an urban hospice agency has financial difficulty unless they enjoy a major fund-raising program and maintain a **large** staff of hospice volunteers to provide the services. This limitation results from the capped Medicare reimbursement of home hospice care at **\$80-90** per day. When continuous nursing care is required for eight or more hours in a day, reimbursement shifts to \$20-22 per hour. A typical hospice receives only 60% of its revenues from third-party payers, and must rely on private donations to make up the **remainder**⁹.

Some unique needs of patients result from geographic and social factors; if unmet, these needs can be major impediments to community-based services. A striking example was the inadequacy of public transportation in one city we studied. Because many patients were financially unable to own a car or travel by taxi, they had serious difficulty keeping medical appointments. To fill this significant service gap, the home care agency incorporated local transportation services into the role of the home health aide. They were **responsible** for driving the patient to the medical appointments, thereby making it feasible to maintain a seriously ill patient at home. The agency stepped in to fill this need, despite the potential liability issues for the agency and the resultant extra time and responsibility for the home health aide. Since all the home health aides had access to a car and were willing to drive, this did not limit the pool of qualified staff for HIV cases.

In another example of program flexibility, a leading home care agency used public grant support to cover their drop-in visits to the local adult day care program and residential facility.. housing many HIV clients. This arrangement has come to be known as a "sick call" program, and provides the day care and residence with a regularly scheduled skilled nursing visit during which any new developments or acute medical needs can be assessed quickly. A daily visit takes the place of employing an on-site nurse, whose presence can overly medicalize the setting and significantly increase operating costs. **In** most cases, the nursing staff is not needed on-site, as long as the drop-in nurse makes regular rounds.

Where funding, sources permit, some home care agencies provide short term or emergency respite for informal caregivers including significant others and family members. The importance of having access to relief from the burdens, both physical and emotional, of providing day to day care at home must be emphasized. The details of how informal caregivers adapt to the role, and methods to support their involvement are reviewed in an upcoming section of this report.

B. Available Data

The Literature contains numerous estimates of the proportion of persons with **HIV illness** who need home care services. Sadly, these figures have not been based on detailed, verifiable data; instead they seem to be the product of "best-guesses" on the **part of specialists in HIV** care. Very few systematic attempts at long-term care needs assessments have been made. **As** a result, home care agencies have functioned in a reactive, crisis-oriented mode to fill immediate gaps and client needs without benefit of thoughtful planning.

Many of the available estimates come from governmental AIDS service planning documents. For example, the home care needs projections include:

- . 27% of persons with AIDS and ARC (Massachusetts 1990);
- . 11.3% of persons with AIDS (New York State 1989);
- . 10.6% of persons with AIDS (San Francisco 1988);

The value of these estimates is tempered by a number of factors that continue to change over time --- the planned expansion of the AIDS definition, prolonged survival and changing disease spectrum, improved medical therapies that are typically lifelong intravenous infusions, evolving demographics of new HIV cases.

Needs/Demand for HIV Home Care Services

The most detailed and specific example of a long term care needs assessment for persons with HIV illness is the product of the New York City AIDS Task Force, released in July 1989¹⁰. While the conclusions may be growing out-of-date as care patterns evolve, the data points to an even greater need for home care than cited within the reports mentioned above.

The approach uses actual AIDS case reports, adjusts to include other HIV illness, and projects future service needs for housing and long-term care through 1993. Actual hospital discharge data and the results of a 1988 New York State AIDS Institute study of **post-discharge** needs -(known as the AIMS survey) serve as the basis of a detailed service needs estimates. The AIMS survey described post-discharge needs using a combination of observable patient characteristics:

- ability of the patient and/or their caregiver to direct the care;
- the patient's functional status;
- available and adequate housing at discharge.

The New York City Task Force assumed that the AIMS survey results are representative of the housing and long-term care needs of adults with HIV **who have at least one acute care hospitalization of 10 days or more during a given year. Also** central to the model are the assumptions that service delivery patterns and the need for housing and long term care services will remain constant during the period. The limitations of this approach are that the service estimates will lag behind the actual need, and the post-discharge needs of people with less frequent or shorter hospitalizations and children with HIV are not included.

With information from the AIMS survey, five levels of service need were developed using a combination of the **patient's/caregiver's** ability to direct care and the level of support services required (as derived from the patient's functional status). Using this matrix approach, 86% of patients were able to direct their care themselves (or had a **caregiver** available to do

so) while 14% could not. Within these groups, patients were classified as needing "low", "medium" and "high" levels of care, with the following results:

- . 51% were self-directing and needed a low level of post-discharge care;
- . 25% were self-directing and needed a medium level of care;
- . 11% were self-directing and needed a high level of care;
- . 6% were non-directing and needed a medium level of care;
- . 8% were non-directing and needed a high level of care.

The largest subgroup (self-directing with low level needs) was assumed to have no functional deficits and would not need in-home personal care or chore service assistance; these individuals are likely to need case management services and intermittent nursing visits for clinical assessment. The medium level of home health support is defined as the need for at least periodic nurse monitoring (i.e. one visit every two weeks) and/or up to 60 hours of home health aide assistance per week. The high level of care is defined as greater than 60 home health aide hours per week and/or two or more hours of continuous skilled nursing service per day; this level would exemplify the long-term home infusion patient with clinical deterioration. The average durations of service for medium and high care levels were assumed to be 120 and 160 days, respectively; the same figures were **used** to estimate the length of stay in long-term care institutional settings (skilled nursing facilities, etc.).

Further refinement of the model identified that 25% of the patients were in need of housing, and therefore excluded from the home care service needs statistics. Another 25% had precarious housing situations that required some intervention to remain in their previous living arrangements after discharge.

Among the striking results of the needs/demand forecast are the projections that from 1991 through 1993 the following will be required for persons with HIV in New York City:

- . 3,000 to 4,000 acute care beds;
- . home care for 2,500 to 3,500 persons per day;
- . high level home care for 600 to 800 persons per day;
- . 81,000 to 110,000 home care nursing visits per year;
- . 520,000 to 710,000 continuous nursing care hours per year;
- . \$121 million to \$194 million home care coverage.

Duration and Intensity of Services Provided

The New York City Task Force report used certain assumptions coupled with actual post-discharge data to project future home care service needs. Most of these assumptions, including those concerning intensity and duration, are based on rough categorical estimates and, although they are obtained from specialists in the field, they are not necessarily grounded in real data.

Similarly, the agencies studied for the development of this analytic synopsis were not regularly monitoring their service utilization statistics. When asked to estimate the average duration of home care service, program coordinators offered a range of figures from 45 to 180 days. While these estimates are consistent with the New York City report at present, future disease trends are likely to extend survival and thereby increase the duration of home care needs.

One study site had information about the intensity of their services to HIV patients; they reported an average of 33 combined service hours (nursing and home health aide) per month and 17 average visits per month. Typically, skilled nursing visits occur twice monthly, and home health aides make 2 or 3 visits (4 hours long) per week. This is comparable to the "medium" intensity category noted in the New York needs assessment.

Another agency in the study reported a more intense pattern of care, based on their general experience and not specific data. The estimate of 1 to 3 **skilled** nursing and 3 to 5 home health aide visits per week would exceed the "medium" level by up to 80% in cost (i.e. \$72 vs. **\$40/day**).

The minimum level of HIV care in home would include the intermittent skilled nursing monitoring and case management role. As funding for case management increases, more home care agencies will begin to routinely offer this level of service and thereby develop relationships with clients earlier, which will be sustained through later periods of more intensive home care needs. The maximum level of home care would be characterized by daily skilled nursing visits and round-the-clock home health aide coverage. According to the agencies we studied, this high intensity extreme is infrequently needed and is limited to a brief period at the terminal stage of illness.

C. Structure of HIV Program

Both specialized and integrated models of HIV services are common in home care agencies, and three of the sites we visited used combinations of HIV-specialized staff and generic nursing support. The larger organizations tend to integrate HIV patients throughout their agency, according to their routine system of case assignment, which is typically by geographic area. The factors that influence an agency's choice of integrating versus specializing HIV include:

- the agency's approach to other special population groups --- the site in our study that was maintaining a specialized model of HIV service delivery has established this precedent with other patient populations, and viewed it as their agency policy.
- the program's historical evolution --- early development usually included supplemental **ding** for an AIDS/HIV coordinator, thereby establishing an agency specialist.
- the various funding sources --- in agencies where multiple grant funding was received, a **specialist** nurse was often hired with grant support and functioned as the coordinator for that specific program's clients; the complicated details of client eligibility rules and

terms of-service reimbursement were best managed by a designated individual for each project.

- the preferences of professional staff --- individual staff members sometimes volunteered to work exclusively with HIV clients, and the agency attempted to support this request. In other instances, nurses requested to have a mixture of the clients with HIV and other patients requiring less intensive care.
- concern about job satisfaction and preventing “burnout” --- one agency’s attempt to establish a workable caseload for special HIV nurse case managers integrated a **case-sharing** approach in which a generalist nurse co-managed patients as their health deteriorated and needed more intense services.

The specific organizational models that were observed in the study sites were surprisingly varied, and serve to illustrate the many structural possibilities. Their specifics are described below.

Site A:

Active HIV caseload = approx. 150
680,000 total agency **visits/yr.**

The structure has been evolving over time, from early years when state funding supported the HIV nurse coordinator. The nurse coordinator served as a resource for other staff, liaison to the network of community-based agencies, and in-service educator concerning the unique issues of HIV disease. Supplemental funding for a part-time clinical social worker was rebudgeted to support a psychiatric **clinical** nurse specialist (CNS), when the administration realized the need to combine broader nursing **skills** with mental health/counseling expertise to meet HIV clients’ needs. Expansion of public funding now supports two FTE psychiatric **CNS’s** who see only HIV clients; their caseload is **15-20** clients and they maintain a waiting list for new clients. The agency still maintains an HIV coordinator for supervisory and liaison functions, but has established a new role for HIV nurse case managers (currently two **FTE**). The HIV case managers each carry a caseload of **15-20** patients and share clients with generalist nurses when their needs accelerate to more than two visits per week. The agency has a specialized IV team, and the IV nurses report that 75% of their caseload are HIV infected; for continuity, the IV nurses are permitted to continue managing their HIV clients after the IV therapy needs are over. Home health aides (**HHA’s**) who wish to be designated as “specialists” are given priority for cases and a chance for more hours; approximately 10% of the agency’s HHA’s have asked to be part of the core team of specialists.

Site B:

Active HIV caseload = 52
218,000 total agency **visits/yr.**

This agency has maintained a totally specialized model, through an AIDS team core group of 3 FTE RN’s, 1 per-visit RN, and 3 HHA’s. This structure is consistent with the **organizational** approach used in the past for managing other specialized clients.

The locus of HIV planning activity within the agency has evolved from the original role of the community development manager to a more integrated effort under the AIDS team manager. Compared to the other three agencies studied, this agency had the most intensive outside interactions with other HIV service network providers; the team manager regularly participated in weekly case management conferences at the public hospital and network-wide. The lack of mental health services or a specialized IV team was also unusual.

Site C:

Active HIV caseload = approx. 300
160,000 total agency visits/yr.

Although the smallest agency visited, this private hospital-based agency had the largest HIV caseload. Given the size of the patient population and the complexity of needs (many families with HIV, commonly related to substance abuse), an integrated approach is **used** for routine nursing visits and specialized nurse case managers coordinate the HRSA grant and the state Medicaid waiver programs. The home health aide coverage is provided under contract by another non-profit agency, a visiting homemaker service. Social workers are heavily involved in the HIV program, providing substance abuse counseling, bereavement counseling and **other** ongoing **mental** health support services and referral. Historically, this state's Medicaid program has reimbursed for **MSW's** involvement in home care, thereby influencing the development of this model.

Site D:

Active HIV caseload = 35
250,000 total agency visits/yr.

This agency has developed a position of HIV nurse coordinator through use of grant funds. Because the individual who holds the position is both an RN and a social worker by training, she has a very broad base of knowledge and **skills** in case management. There are specialized **HHA's** who prefer clients with HIV; **1/3** of the **HI-IA's** have chosen to join the specialty group, but the agency permits other **HHA's** to refuse patients with HIV. The other skilled nursing needs are provided by generalist nurses, by routine integration of case assignments; the nursing staff cannot decline acceptance of an HIV-infected client. There is no formal IV team, but a core group of RN's are known to prefer patients receiving IV infusions.

D. Ongoing Research in HIV Home Care

The complexity of this rapidly changing field cause major difficulties in the projection of service needs and program development. There is research work in progress that will build on the recent past experience with HIV home care:

- The Foundation for Hospice and **Homecare** is analyzing results of a national survey, which describes the extent of involvement and current problems reported by their member agencies; information may be available in late 1992.

· A study funded by the Agency for Health Care Policy and Research (AHCPR) and conducted by the University of Maryland School of Nursing focuses on 14 states, ranking 6th through 19th in AIDS incidence. This study surveys all licensed home care agencies, and collects descriptive information from the Medicaid and the HIV/AIDS programs relative to funding policies and program plans; results are anticipated by mid-1992.

. In Columbus, Ohio, an experimental evaluation of multidisciplinary case management versus routine community-based care is underway; outcomes of interest include patient satisfaction, costs and functional status. Enrollment is running below projections, but the 3-year project ends in late 1992.

IV. CAREGIVER ISSUES

A. Formal Caregivers

Professional Staff

The home care professional staff includes registered and practical nurses, therapists, and social workers. There have been intermittent manpower shortages in the health care field, and many feared that concern about occupational HIV risks would exacerbate these problems and drive professionals out of HIV care situations. However, the sites studied here did not report any current shortages. In fact, one agency now has an applicant waiting list for RN positions. As the nursing shortage waxes and wanes, home care agencies have sometimes found it difficult to compete with hospitals' salary and benefit packages. Perhaps the current economic recession has led to greater stability in the health manpower area, and **will** continue to promote a greater influx of new nurses and other professionals into the field.

There were no significant difficulties in recruitment of home care professional staff. Intensive in-service education concerning HIV was instrumental in overcoming fears and providing specialized knowledge. **All** programs we studied have adhered to personnel policies that require RN's and other professional staff to accept HIV client assignments. In programs with an HIV "specialist" assignment, the RN's request or volunteer for this designation. Organizationally, there may be a need to upgrade the HIV nurse specialist positions so that a higher salary and elevated career status would diminish turnover and improve job satisfaction in this stressful role.

Because the intensity of needs and terminal nature of the illness combine to make HIV care highly demanding, productivity standards for HIV specialists are adjusted compared to those of generalist nurses. For example, salaried full-time RN's in two study agencies must make 31.5 and 26 visits per week, respectively; productivity expectations for their HIV specialist nurses is reduced by 27-44%, to 17.5 and 19 visits per week, respectively.

Another mechanism for staff support is the initiation of formalized support groups for discussion of issues resulting from HIV care involvement.

Paraprofessional Staff

Homemakers and home health aides play an essential role in HIV home care. They often fill the critical need for personal care assistance and light housekeeping tasks, permitting a patient to stay at home as symptoms of weakness, mental confusion and fatigue become more prominent. A serious shortage of paraprofessionals for HIV care marked the early years of the epidemic, stemming from the reluctance of individual home health aides to accept HIV patients and difficulties in obtaining recruitment for these services. To some extent, this scenario is repeated in each new agency and geographic area that encounters its first client with HIV in need of home care services. Anecdotes from low incidence areas confirm an initial period of anxiety and fear, followed by gradual enlightenment and ultimate acceptance of patients with HIV disease. No matter how much progress has been made in AIDS/HIV awareness at the macro level, each agency and individual provider goes through predictable stages of reacting to an HIV client.

The study sites had overcome initial difficulties in recruiting home health aides and homemakers, often through special training and support group efforts. Only one of the four sites offered a differential rate of pay for clients with HIV illness. They justified this action on the basis of an existing precedent for high-intensity cases paying \$0.25 per hour more than routine cases. Prior to patients with HIV, this specialty category applied to certain pediatric cases, where family violence made protection of patient safety a key service.

Home health aides receive certification following the completion of a required level of training. Most agencies now provide training concerning HIV and infection control procedures to all their home health aides. Salaries for home health aides ranged from \$6 to \$8 per hour. Some agencies operate a specialty group for home health aides, for cases such as HIV clients and inclusion in the specialty pool brings advantages for more assignments and hours. In most cases, agencies have established support groups for staff caring for clients with HIV; not all of these offer pay for attendance in the groups.

The impact of HIV work on outside personal relationships is an issue for both professional and paraprofessional staff. Husbands and children are often anxious about the risk of their wives and mothers caring for an HIV client. Agencies have organized information sessions and counseling for the family members, but the turnout for such events has been disappointing. In many cases, the employee's reluctance to accept a patient with HIV stems, not from their own fear, but from the demands of their family. Hopefully, as time goes on and the general public continues to learn about HIV disease, these influences will be diminishing.

B. Informal Caregivers

The valuable contributions of informal caregivers -- spouses, lovers, family members, and friends -- are often the factor that permits a patient to remain at home. Studies in the elderly have shown that more than 80% of the care is performed by informal caregivers; in HIV disease, the additional assistance of volunteers or "buddies" organized through AIDS service organizations (ASO) most likely increases this statistic.

The needs of informal caregivers include support, training and respite. Agencies nationwide, including home care providers, are attempting to maintain this valuable resource by developing specialized programs to suit their needs. In Boston, a volunteer group offers short term respite in-home when the caregiver requests coverage. The **opportunity** to get out for a movie, a shopping trip, or another social outlet is deeply appreciated by most caregivers on an occasional basis. Training in basic personal care techniques and the forum to ask questions about mundane concerns (infection control at home, disinfection, food preparation, etc.) has been regularly offered for caregivers through an **ASO**.

Availability of various complementary programs including home-delivered meals, adult day care, institutional respite care, homemaker/home health aide service is key to sustaining the role of the informal caregiver. Options for financial reimbursement are being considered, but to date have not been widely implemented.

In rural areas, the role of volunteers is most important. For example, in one small community the ASO arranges volunteer coverage for round-the-clock assistance of very ill patients. This assistance is the difference between staying home or being admitted to a distant hospital, and successfully supports periods of increased illness and need for assistance. In these locations, intermediate care facilities or services are not generally available and home care staff is limited.

V. CASE MANAGEMENT

A. Experience in HIV Service Networks

The term "case management" has been loosely applied in various aspects of HIV care, and is considered the essential ingredient of a comprehensive HIV community-care program. The Brown University research team that evaluated the initial **AIDS** service demonstration projects funded by the Robert Wood Johnson Foundation (RWJ) has described the phenomenon of HIV case management in detail". Briefly, there are five components of case management:

- 1) intake and assessment -- of medical and social needs, and program/entitlement eligibility; best done early in illness, while operating in a "non-crisis" mode.
- 2) care plan development -- should be well-documented, particularly when turnover and burnout can result in frequent reassignment of the client's case manager;
- 3) monitoring of service delivery -- the most difficult function, it has been minimally carried out in HIV care;
- 4) linkage to services -- the most time-consuming and involved;
- 5) advocating -- occurs both at the system and client level, to remove general gaps and barriers and solve individual problems; this includes gaining access to entitlements, insurance and disability benefits.

Sites of the RWJ demonstration program employed various models of case management: centralized within a single agency whose function was limited to “care coordination”; run from a multidimensional AIDS Service Organization (ASO) by nurses (in one city) or baccalaureate level allied health workers; used primarily to triage clients during acute situations; multilevel systems with sophisticated tracking and triage functions for moving clients in and out of case management; “outstationing” ASO staff to hospital clinics; decentralized with multiple sources of case management. Strengths and limitations can be identified for each approach, but the evaluators emphasized the following points:

- 1) Triage is necessary at some level, to prevent’ overloading the system and inappropriate service delivery;
- 2) Information and referral systems should be strengthened, and automated case management systems implemented whenever possible;
- 3) Systematic record keeping and documentation is critical;
- 4) Case managers can have varied backgrounds, but they should have allied health training; one group that is well-suited to the role are bachelor-level social workers;
- 5) The case manager’s effectiveness is linked to their agency-affiliation, their own skills, level of training and experience.

They found clients frequently confused about the locus of their own case management. Interviews with nearly 1000 clients revealed that 28% did not know they were receiving case management, and 10% identified dual sources of case management. During the site visits conducted for this project, we found some of the same confusion and occasional duplication of case management services.

B. Role of Case Management within Home Care Program

The role of case management in HIV home care programs is viewed with similar importance. Home care agencies are serving variously as providers and targets of case management. Home care services are among the array of programs to which the clients need linkage; however, these usually are arranged, at least initially, by the hospital discharge planner and physician following an acute care inpatient hospitalization. There is a recent effort to incorporate home care earlier in the course of a client’s illness, to serve as a “user-friendly” and cost-effective outpatient medical care provider, monitoring their clinical status and other psychosocial service needs before other technically complex **nursing** or intensive personal care needs arise.

The function of the professional nurse within the home care agency is now often considered to be “case manager”. Use of this term may be in part a reflection of “HIV service jargon”, but it is meant to reflect responsibilities beyond the simple provision of direct nursing care. Within the agency, the nurse case managers are distinct from other registered nurses in that they are the HIV specialists. They conduct the assessment, determine eligibility

for coverage and services, and develop a specific care plan for each client. Nursing expertise is well suited to these activities, and clients establish a formal relationship with an individual nurse, who will be their ally and advisor as clinical and social needs arise for them and their families.

C. Approaches to Community Care Case Management Program Evaluation

While health services research in HIV gains momentum and maturity, valuable lessons can be gleaned from the multitude of studies aimed at evaluating the benefits and cost impact of home- and community-based services for the elderly. Acknowledging the important difference in access to nursing home options between geriatric and HIV clients, there may be enough commonality in needs for case management and in-home services to warrant attention to the conclusions of earlier work.

For example, a review of the geriatric demonstration and research **projects**¹² that saved money yields the following themes:

- While not demonstrating improved survival, home care systems in 90% of studies showed benefits in “life satisfaction” and other measures of psychosocial outcome.
- Differences in physical and mental functioning varied by subpopulations, with the more stable and independent patients likely to benefit from m-home care.
- Home care savings were generally realized during the first few months of service, often followed by later losses when patients remain on caseload.
- Unusually expensive “outlier” cases often accounted for the comparative savings. These “outlier” patterns of utilization were eliminated by service coordination.
- . Respite care, serving as a bridge between hospital and home, was a critical factor in one study where a sheltered housing unit was reserved for short-term use (less than 2 weeks).
- The existence of a congregate housing facility or supervised residence was key to several successful programs.
- . There was a tendency for home- and community-care programs to operate inefficiently due to excess capacity and lack of utilization review; improved efficiency and the resultant low cost of the intervention cause even minimal effectiveness to yield a savings.

There is one other major finding in geriatric research that should be considered carefully for HIV programs, since it indicates that what is best for the patient’s health status may not be the most cost-effective. The research pointed out that younger, minimally disabled persons with support in the home were most likely to benefit from home and **community-**based care, while older, severely disabled patients without support became more dependent at home compared to their nursing home counterparts (**Weissert, 1988**). Since cost savings

was most often the result of nursing home avoidance, the conflict between the desired health status outcome and cost savings may prohibit realization of simple cost-efficacy. While savings may be difficult to demonstrate, the substitution of lower cost services for higher cost services will permit more consistent and comprehensive care over a longer time interval, and is expected to be preferred by the majority of patients.

D. Automated Case Management Systems

As caseloads continue to grow and more agencies become involved in **community-**based HIV care, the need to efficiently manage client-level information will be magnified. Fortunately, considerable attention has already been devoted, within the field of **computer-**based information specialists, to the development of comprehensive yet "user-friendly" systems. There are several software systems that are being used by AIDS service organizations for case management documentation. In the course of this project, we encountered two examples of such systems, the ECHO System (Conway, NH) and IMACS, developed by Automated Case Management Systems, **Inc** (Los Angeles, CA). To complete our report, we also investigated the third version used by AIDS Service Organizations---COMPASS, developed by Health Systems Technology (Fairfax Station, VA).

COMPASS System: Health Systems Technology has installed the COMPASS long-term care case management software in 25 agencies, across 15 states since its inception in 1984. The COMPASS System has been customized for the HIV service environment to accommodate diverse information needs. COMPASS clients include the AIDS Foundation of Chicago, Whitman Walker Clinic of Washington, DC, and two Michigan-based AIDS Service Organizations. Aspects of the system include the intake record, assessment instrument, monthly data reports, resource directory, quality assurance, and **local** area network capacity. We could not identify any home care agencies currently using the COMPASS System.

ECHO System: The ECHO Company is well established in the field of automated systems for substance abuse, mental health and children/family services; they have 400 installations serving agencies in 45 states. The original site for the ECHO AIDS Case Management System was the Gay Men's Health Crisis of New York City. In late 1988, they installed the system that currently included 50 workstations. We observed the system in use at one of our study sites, where the case managers we spoke to reported some discomfort and dissatisfaction with the operations. The long term goal of networking the relevant agencies was being delayed for a variety of reasons; this left the staff feeling that the utility of the system was incomplete. Other clients include Dallas AIDS Resource Center, the AIDS Action Committee of Massachusetts, and agencies in Norfolk VA and Honolulu, HI. These systems do not involve networking outside the agencies, however. Therefore, home care data is not input directly by the provider agency.

IMACS System: The IMACS is now in use at the Los Angeles County Health Department's (LACHD) AIDS Program, and as a result it may be the most widely tested system at this time. Other agencies have been proceeding slowly to **operationalize** an automated system, and to our knowledge, none have networked them among groups of separate agencies.

According to Theresa Wisda (**LACHD**), funding from **the** Ryan White CARE Act has been used (based on their case management committee's recommendation) to purchase computer hardware, the software system, training, and a resources database for expansion of the network to include out-patient clinics and other medical care agencies. Several **community**-based organizations and 1 city agency are using the decentralized system. The "case-net" module links the participating agencies through phone modem connections using a unique patient identification code so that case managers can determine if the individual client is already receiving services from another participating agency. Each client signs a information release form concerning the information system at the point of intake into the service network.

In their experience, agencies that have their own systems manager on staff are able to implement the system easily, and take full advantage of its capabilities; these include AIDS Project Los Angeles and the Gay and Lesbian Community Service Center which have up to 30 terminals operating. At AIDS Project Los Angeles, the system is utilized throughout the agency including the food bank and mental health sections, in addition to the case managers. Smaller agencies that are single-user systems have been having more difficulty overcoming initial resistance, fear of abandoning a "paper document-based" system, and learning to fully use the software.

The most knowledgeable users have recognized the benefits of the automated approach, including a tickler system that reminds the case manager of actions needed, schedule for follow-up calls, etc. An additional advantage is that the unique client identification code serves to point out duplication of service delivery when a client is being case managed by another agency using the system. The automated approach has not completely replaced those frequent interagency phone calls, however.

The IMACS system has several other modules including grants management, the HIV resource database, a service plan, appointment scheduling, report generation. The reporting module is being revised to include data called for in **HRSA's** Uniform Reporting System for grants to cities and states under Titles **I** and **II** of the Ryan White **CARE** Act. The system is affordable for most agencies, and the potential increased efficiency for case managers and other key staff saves additional money and resources.

The IMACS, **COMPASS**, and ECHO systems differ in their operating systems, and these differences have cost implications beyond the initial software investment. The COMPASS and ECHO Systems are DOS-based and use IBM-compatible microcomputers. The IMACS system is UNIX-based, and agencies with existing computer systems are more **likely** to be using DOS. In addition, software for UNIX-based systems tends to be much more expensive than the DOS-based version, resulting in higher auxiliary computer system costs.

Despite these differences, all three systems intend to make their data elements and reports consistent with the HRSA Uniform Reporting specifications. We anticipate an important role for these and other automated case management systems in the coming years, as CARE Act recipient agencies nationwide **realize** the potential of this approach.

VI. ALTERNATIVE SETTINGS

A. Day Care Programs

One alternative approach to community care is the monitoring of patients in groups during **the** daytime hours, a model not dissimilar from day care for children. The goals of day care for adults also mirror those of day care for children -- to provide supervision while the usual caretaker goes to work, to facilitate socialization, group activities, and individual assistance and learning. Most day care programs for adults with HIV illness attempt to downplay their medical aspects, preferring to create a homelike, welcoming environment without constant reminders of illness and disease.

In Dallas, the Daire Center is a example of a program that has continued to operate **successfully** outside of a traditional system of reimbursement and medicalization. Their operating budget is modest, and funds come from grants (Robert Wood Johnson, HRSA Demonstration, Ryan White **CARE** Act) rather than Medicaid. This approach builds in flexibility and avoids the restrictive regulations imposed by Medicaid, which requires clients to attend a minimum of twice a week and dictates certain features of the physical facility to obtain **licensure/certification**.

Through a relationship with the visiting nurse agency, a nurse from the HIV team routinely drops in to assess any immediate needs in the center at large, and to conduct routine treatments for ongoing home care clients on-site. This provides adequate safety and efficiency, and permits a more homelike atmosphere that has been the key to the center's success. In addition, the center is located in a pleasant and convenient residential neighborhood, and transportation is provided by a center employee for those in need.

A slightly more clinical approach exists in Denver, where the Center for Nursing Caring combines personnel and other resources from the city's three medical centers (Veteran's Administration, University and City/County) in a unique model. A treatment center primarily, blood transfusions and infusions are performed by nursing staff on-site; these services are charged and reimbursed through typical channels according to the policies of the referring hospital. Other activities are integrated into the center's activities, including groups for peer support, supervised day care and group activities such as aerobics and other crafts or hobbies.

One reason for the success and popularity of these two programs is the homogeneity of their patient populations. In these cities, the demographics of HIV infection have consistently shown white, homosexual men are the predominant group; therefore, they comprise 90% of consumers of these services. AU congregate care programs become more difficult to organize, operate and sustain in areas with more diversity among their consumer populations. Where continuing drug use is common, there are additional safety and legal issues that overlay attempts to conduct community care programs of this type.

Other cities are attempting to establish day care programs, using conventional and non-conventional approaches. In Boston, federal funds were secured for renovation of a facility with the plan to initiate a day care program. The location and context of this facility made it difficult to identify a vendor agency to set up and operate **the** program. The site is an

upper floor of- the state public health hospital, making a homelike atmosphere virtually impossible to create. The building's location is suboptimal, on the fringe of public transportation routes and in a remote, somewhat dangerous neighborhood of the city.

However, a local agency heavily involved in housing programs for clients with HIV was selected to run the day care program. It opened in February 1992 for 15 to 30 clients. Medicaid reimbursement has been negotiated at \$67 per day, compared to the \$30 daily rate for geriatric day care centers. Clients must attend at least 2 days per week to receive Medicaid coverage. After initial difficulties with staff turnover, their current problem is the sporadic patient census and ongoing difficulty keeping the spots filled. After bureaucratic snags to agree on reimbursement with the Veteran's Administration (VA) Hospital nearby, VA clients are now attending regularly. As expected, many of the patients have significant **neurologic** involvement and functional impairment. They have created a very nurturing environment, with many activities and special programs, and operate a van to transport clients to and from the center.

There was a former unsuccessful attempt to create such a program in Boston, based in a Catholic long-term care hospital; this unit closed after less than one year, citing lack of demand and difficulties in management. This experience underscores the importance of suitable location, desirable atmosphere, accessible transportation and creative management to the success of these programs.

B. Institutional Alternatives

In-patient hospice programs

The hospice care movement has gained widespread acceptance throughout the world over the past two decades. It represents a holistic interdisciplinary model of care for the terminally ill, incorporating spiritual, palliative, and psychosocial dimensions to maximize the quality of life. In the United States, home-based hospice care is widely available and many institutional hospices operate as well. Short term services (less than six months by definition, but some states are extending this **time** limit for HIV patients) are provided to terminal patients and their families; the **typical** client has been elderly and dying of cancer.

The early experience with AIDS was an appropriate match with the traditional philosophy and functional policies of hospice care, because the illness followed a predictable terminal course and no specific interventions or treatments were yet available. Initial apprehensions of hospice programs and workers were quickly overcome in most cities, and considerable involvement in care of terminal **AIDS** patients has been observed. In fact, specialized hospice programs, including both home-based and institutional facilities, have been established in many cities. For example, the Visiting Nurses and Hospice of San Francisco established **the** AIDS Home Care and Hospice program and a residential facility known as Coming Home Hospice. In Boston, the Hospice at Mission Hill was developed with combined federal, state and private support to deliver specialized services to AIDS patients at an 18-bed free standing facility in a residential location.

However, the rapid development of medical therapy for HIV infection and associated opportunistic diseases and malignancies has resulted in a major dilemma for patients, physicians and hospice providers. The success of antiviral treatment has prolonged survival and significantly modified the spectrum of opportunistic infections. The original scenario in which patients succumbed to Pneumocystis carinii pneumonia has been altered because of prophylaxis, and other late-stage manifestations of immune suppression are becoming commonplace: disseminated infection with cytomegalovirus (CMV) or atypical mycobacterium and high-grade lymphomas.

Thanks to major therapeutic breakthroughs, all of these problems are now treatable, and while not usually “curable”, the pace of clinical deterioration can be slowed with medications. The drawbacks are that these drugs cause major toxicity and must be administered parenterally for the remainder of the patient’s life. The important positive results include prevention of blindness, suppression of extreme fevers and night sweats, improved level of energy and decreased wasting or diarrhea. To further complicate the situation, many of the best treatments become available prior to FDA approval and marketing, under experimental treatment protocols or “compassionate use”/expanded access programs. The complex paperwork, elaborate monitoring for side effects, and research nature of the drug’s use are foreign to the hospice care system.

Hospice programs typically restrict intravenous therapy, which is naturally more aggressive and invasive than their overall treatment plan. Outside of HIV disease, technical interventions of this type would not be widely utilized or offer major benefits. Cancer patients receiving hospice care have typically foregone aggressive interventions and elected emotional and social support with palliative symptom control---the mission of traditional hospice programs.

Today, patients with end-stage HIV disease face significant obstacles to hospice care. First, they must abandon aggressive medical treatment and decline participation in clinical research protocols. The typically young age of AIDS patients combined with the extraordinarily rapid pace of treatment developments leave most individuals optimistic for prolonged survival and unwilling to embrace the hospice model. The illness has become increasingly unpredictable, and many patients have personally experienced (or witnessed in other patients) seemingly miraculous recoveries from serious clinical problems; this dynamic adds to their reluctance to define their illness as terminal.

When patients finally decide to enter hospice care, it is very late and at a chaotic point. This is evidenced by the relatively short length of stay at Boston’s facility---typically between 7 and 21 days. Hospice staff have little time to establish rapport and provide the essential psychosocial support to the patient, their family, and friends. Therefore, the quality of their hospice experience is further compromised.

During the site visits conducted for this project, a recurrent theme expressed by providers of residential and home care services concerned the relationship of long-term care for HIV and the hospice approach. They noted that a conflict has now emerged between a new “standard of care” in end-stage AIDS that is inherently “hi-tech” and the admission criteria of hospice programs. Specifically, patients receiving intravenous ganciclovir or foscarnet for

CMV retinitis are denied entry into hospice programs. They are forced to abandon the sight-preserving treatment in order to avail themselves of the multidisciplinary hospice services.

Consequently, residential hospices have become underutilized in some cities. Boston's AIDS-specific hospice has recently been forced to admit other terminal patients (without AIDS) in order to keep their census up. The long-term outlook can best be characterized as continuing the trend toward "hi-tech" palliative treatment and unpredictable disease course, thereby diverging further from the traditional hospice model for more and more severely ill patients.

Supportive Residences

The geriatric care demonstrations described above identified the value of a congregate housing program in improving efficiency and success of home- and community-care programs for some patients. Numerous attempts are being made to establish programs for clients with HIV illness across the country. For details of these activities, please refer to the companion document prepared as part of this project --- "Analytic Synopsis of Residential Services for People Living with HIV/AIDS".

Skilled Nursing Facilities

A lingering shortfall in the field of long-term care of patients with HIV is the lack of available and appropriate nursing home beds. When care outside of the home becomes necessary, because of the lack of a suitable home environment or the absence of a person (family member, significant other or friend) to provide consistent informal care, few alternatives exist in most locations. In New York City for example, nearly 10,000 persons were living with AIDS in early 1990, and only 130 skilled nursing facility (SNF) beds were **available to them**¹³. This ratio of 1 bed for every 77 persons seems pitifully low, but the leadership and creative development work conducted in New York sets it apart from most other areas; therefore, it probably represents the upper end of SNF bed availability at present. One estimate projects that only 1500 such beds will be available in the entire country next year (1993)¹⁴.

New Jersey attempted to remedy this situation by selecting a single nursing home and negotiating a special reimbursement rate for HIV patients. The **240-bed** facility had 180 geriatric and 60 chronic pediatric beds until 1988, when it **set up an 80-bed** dedicated AIDS unit¹⁵. The average length of stay became more prolonged over time, from 8 to 12 weeks; census rates have remained high. The program has experienced many challenges in its attempt to serve diverse patients at various stages of illness. A similar program in Philadelphia reports more prolonged stays, with 10% of their patients staying for over 1 year; 20% were able to be discharged home after receiving intensive therapy and nutritional **support**¹⁶. Patients who expired at the nursing home (70%) received care for an average 11 weeks.

In the experience of programs cited above, a "critical mass" of eligible patients is required to justify and support the multidisciplinary approach needed for a specialized unit. However, without a specialty unit individual patients cared for in nursing home settings

sometimes feel isolated, abandoned or vulnerable to discrimination. Recommendations from a successful nursing home program include the need for”:

- procedures specific to the needs of patients with HIV;
- increased social services;
- ongoing support groups;
- services for substance abuse recovery (e.g. Alcoholics Anonymous and/or Narcotics Anonymous);
- policies and strategies for dealing with substance use in the facility;
- consistently available education and support for staff:

As the clinical spectrum of HIV and new avenues of treatment evolve, longer term technical care may become an even greater need, sometimes surpassing the reasonable scope of in-home services. The burgeoning caseloads may overshadow the existing caregiver supports (family, lovers, volunteers), leading to a breakdown in the current home care pattern. Many newly diagnosed patients with HIV are homeless or precariously housed, further increasing demands for institutional care options. For all of these reasons, efforts should be stepped up in the field of long-term care resource development including suitable nursing home alternatives.

VII. CONCLUSIONS

. Importance of home care services for clients with HIV

Throughout each level of our study, we found that home health care was an essential element of comprehensive service networks for persons with HIV illness. Current clinical trends, such as improved survival and the availability of long-term infusion treatments, suggest that home care services will be increasingly important for patients with **HIV in the future**. Most patients and providers prefer the option of home care, because it preserves independence, promotes continued contact with and support from loved ones, utilizes a familiar, comfortable environment, is most flexible and responsive to sudden changes in status and needs, and is generally less costly than acute hospitalization and other institutional alternatives.

. Responsiveness of home care agencies to new needs and problems

The agencies we studied demonstrated unusual creativity and vision in their ability to develop new programs to **fill** significant gaps in the continuum of community-based **HIV** care. Home care agencies are ideally suited to this role, since they are widely established within their service area, have the appropriate health service capacity (e.g. professional **staff**) to respond to clinical challenges, and have well-integrated paraprofessional, social service and mental health expertise that is essential to HIV care. They identified and responded swiftly to needs for transportation, meals, respite, informal caregiver training, bereavement counseling, and intermittent nursing coverage in a variety of community-based settings, as long as grant funding or reimbursement was available.

. Influence of reimbursement limitations on care delivery

Funding policies for home care are inconsistent and often inappropriate for a young client with complicated chronic disease who is often unemployed, living alone, and away from family. Policies concerning home care benefits were developed with the elderly client in mind, yet HIV home care is being provided within the limitations of these reimbursement specifications. Currently, inadequacies of Medicaid home care benefits are posing the greatest difficulties. They restrict certain necessary services and often fail to reimburse adequately for less skilled care. In addition, restrictive criteria imposed by HIV specialty grants further constrain the delivery of appropriate home care services.

A major financing issue for all home care agencies is the visit-based, rather than time-based, reimbursement system for skilled nursing visits. Under this arrangement, the agency receives the same flat rate (typically \$60) for a **15-minute** blood pressure check as they do for a **3-hour** complicated infusion visit. This policy severely penalizes agencies providing extensive HIV care, because the average length of visits to clients with HIV is **29-100%** longer than other home care clients. Furthermore, many state programs (e.g. Medicaid waivers) have capped daily home care coverage at \$63, calculated as 65% of their daily nursing home reimbursement rate, even when nursing home options fail to exist.

As more clients with HIV become Medicare-eligible, the requirement that patients be homebound and in need of intermittent skilled care will pose new difficulties. Also, Medicare's limited period of coverage and narrow infusion reimbursement (that does not include the drug cost) **will** become a serious problem.

. Favorable cost comparison vs. acute care and other available institutional alternatives

The cost-effectiveness of home care for the elderly has been **difficult** to document compared to skilled nursing facilities. Cost comparisons of home vs. institutional long-term care options for persons with HIV illness are purely a hypothetical exercise in most locations. There are currently very few nursing homes that provide care to clients with HIV. For approximately the cost of the Medicaid daily nursing home rate (**\$97**), an **HIV** client can receive one skilled nursing visit weekly and 5-6 hours of home health aide assistance per day. The **daily** home care costs for most patients receiving infusion therapy (e.g. for cytomegalovirus infection) would exceed the Medicaid nursing home rate. The highest acuity level for home care (i.e. daily skilled nursing and round-the-clock home health aide) costs approximately **\$450/day**, within the range of acute care **daily** rates; however, this level of care is rarely needed for more than a few days (i.e. episodic illness or terminal care).

. Case management role of the home care agency

The complex needs of patients with HIV and the intricacies of their care raise many management issues. In addition, the rapidly evolving cadre of community service agencies and **resources** pose a challenge to the **primary** care provider. Many approaches to case management for HIV-infected clients have been developed, using AIDS service organizations, physicians, nurses and social workers; these case managers are based in various agencies

including new free-standing, community-based entities with HIV case management as their **singular** mission.

Home care providers are effective case managers, because many community-based care needs can often be met directly through their agency's services. They tend to be well acquainted and connected with other support services (i.e. home meal delivery), and their strong medical/nursing case management capacity offers advantages over a strictly social service approach. Our study sites were successfully developing and refining the role of HIV nurse case manager, an individual with specific oversight and coordination responsibilities in the community.

A more important issue than who provides case management is the potential confusion and fragmentation that occurs when more than one case manager is functioning for an individual client. As the landscape of potential providers expands, effective interagency communication and documentation become more critical to assuring coordinated care and preventing this duplication.

. Reliance on paraprofessionals and informal caregivers

While skilled nursing is an essential component of home-based care in HIV illness, more patients rely on assistance with activities of daily living to keep them out of acute and long-term care institutions. Informal caregivers (**partners**, family members, friends and volunteers) and paraprofessional home care staff (homemakers, personal care attendants, home health aides) provide assistance with cooking, cleaning, shopping, personal hygiene and other essential daily tasks. Third party payors tend to limit coverage for paraprofessional services, and **informal** caregivers face many conflicting financial and emotional demands.

Creative approaches are needed to support informal caregivers financially and emotionally, and provide intermittent respite through back-up volunteer or home care agency coverage. With adequate reimbursement for the effective use of home health aides and homemakers (through private and public sources), institutionalization can be avoided or substantially delayed.

. Lack of specific database and research concerning utilization patterns, need and specific target populations

Many leading agencies in HIV home care have developed a wealth of experience and useful information over a decade of providing services. Unfortunately, the specific data documenting their growth, costs, range of services utilized, patterns of care, and trends in target populations have not been systematically collected and are not readily retrievable. Providers have struggled daily to meet patients needs, often without technical and administrative resources to document, review, analyze and evaluate their experience on an agency-wide or population basis. This is a missed opportunity that limits both the home care industry's perspective and the public sector's ability to plan for resource allocation and influence reimbursement policy. Prospective research and monitoring of utilization trends will be essential for future development of policy and specialized programs.

REFERENCES

1. Benjamin, A. E., Lee, P.R. & Solkowitz, S.N. (1988). Long-term care and AIDS: Perspectives from experience with the elderly. Milbank Memorial Fund Quarterly/Health and Society, **66**, 415-443.
2. Weissert, W.G., Cready, C.M. & Pawelak, J.E. (1988). The past and future of home- and community-based long-term care. The Milbank Quarterly, **66**, 309-388.
3. Staff. (1990, January). Residential and home health care for people with AIDS and HIV-related illnesses. New York State Journal of Medicine, 43-44.
4. Jeffery, L. (1988). Home health care services for people with AIDS: Enhanced capacity through supplemental state funding. In D. Richter (Ed.), Managing AIDS services and resources (pp. 46-49). Charleston, SC: University of South Carolina School of Public Health and Health Resources and Services Administration.
5. Hardy, W.D., Holzman, R.S., Feinberg, J., et al (1992). Trimethoprim-sulfamethoxazole vs. aerosolized pentamidine for secondary prophylaxis of pneumocystis carinii pneumonia in AIDS patients: a prospective, randomized, controlled clinical trial (ACTG 021). Third European Conference on Clinical Aspects and Treatment of HIV Infection, Paris, France,
6. Centers for Disease Control (1992). Recommendations for prophylaxis against Pneumocystis carinii pneumonia for adults and adolescents infected with human immunodeficiency virus. MMWR; 41: RR-4, 1-11.
7. Health Care Financing Administration, Office of the Actuary (1990). Financing health care for people with AIDS: The role of the Health Care Financing Administration. Washington, DC.: U.S. Government Printing Office.
8. Laudicina, S.S. & Burwell, B. (1988). A profile of Medicaid home and community-based care waivers, 1985: Findings of a national survey. Journal of Health Politics, Policy and Law, **13** (3), 525-546.
9. Kane, R.A. & Smith, D. (1989). Multiple perspectives on AIDS and the nursing home: A pilot study and recommendations for research. (DHHS Publication No. PB90-101320, Washington, DC: US Department of Commerce, National Technical Information Service.

10. New York City Department of Health (1989). New York City AIDS Task Force Report.
11. Mor, **V., Piette, J., & Fleishman, J.** (1989). Community-based case management for persons with AIDS. Health Affairs, Winter 1989.
12. Weissert, W.G., Cready, C.M. & Pawelak, J.E. (1988). The past and future of home- and community-based long-term care. The Milbank Quarterly, 66, 309-388.
13. **Flaskerud, J. & Ungvarski, P.** (1992). Community -based and long-term care. In HIV/AIDS: A guide to nursing care (pp. 303-311). Philadelphia: W.B. Saunders co.
14. Taravella, S. (1990). Who will provide long-term care for AIDS patients? Modern Health Care; **20 (12)**, 38-39.
15. Minnefor, A., Lazovita, S., Mondrone, R., et al (1990). A nursing home model for care of AIDS patients: A 3 year experience. Sixth International Conference on AIDS, San Francisco, June **20-24**, abstract WD 4060.
16. Silverman, M. (1990). Outcome of HIV-1 infected patients admitted to the AIDS unit at the Philadelphia nursing home. Sixth International Conference on AIDS, San Francisco, June 20-24, abstract WD 4061.
17. Dunn, S. (1990). Providing care in a county nursing home AIDS unit. In V.E. Fransen (ed.), Proceedings: AIDS prevention and services workshop (pp. 116-119). Princeton, NJ: **Robert Wood Johnson Foundation**.

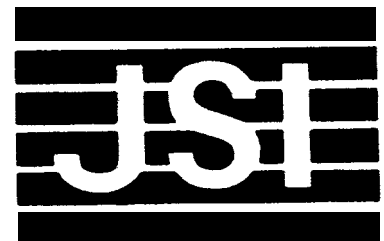
The Formation and Operation of Coalitions to Provide Health Care Services to People with HIV Illness

Analytic Synopsis

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THE FORMATION AND OPERATION OF COALITIONS TO PROVIDE HEALTH CARE SERVICES TO PEOPLE WITH HIV ILLNESS

Executive Summary

Final Draft

During the decade of the 1980s, the programmatic and financial capacities of health and other care services have been severely strained by the rapid growth in AIDS and HIV-related illnesses. Adoption of a "coalition approach" (i.e. collaborating on decisions and services) has proved to be one of the more effective means of improving the quality and quantity of services.

This report summarizes the results of a study commissioned by the Bureau of Resource Development (BRD) within the Health Resources and Services Administration (HRSA) and conducted by John Snow Inc., (JSI). The study focused on the development and operation of coalitions formed to facilitate the provision of health and related services to persons directly and indirectly affected with HIV disease and AIDS.

The opening chapter of this analytic synopsis of the study's findings describes the research methodology, which included a literature review, site visits to four major metropolitan areas, and telephone interviews with HIV coalition members and beneficiaries across the United States. In addition, **Chapter I** offers a working definition of the term "coalition" and describes in some detail the history and characteristics of the four main coalitions that were the subjects of in-depth site visits.

Chapters II, III, and IV examine each of the three basic development phases which most HIV-related (and other) coalitions undergo in their path to maturity -- coalition creation, coalition building, and coalition maintenance, respectively. We have found it useful to categorize the process of coalition development within this framework, since coalitions at each stage of development exhibit and experience similar organizational characteristics and constraints.

Certain qualitative and quantitative factors (for example, leadership and access to funding) are important during all three phases of coalition development; others, such as recruitment, organizational and management skills, or funding appraisal and project evaluation procedures assume varying importance at different stages in the coalition's life. Chapters II, III, and IV deal in considerable detail with these issues and with **parallel** coalition concerns and responses to them during each phase of development.

Chapter V highlights the specific accomplishments and benefits resulting from a coalition approach to providing HIV-related services. The evidence on the impact of HIV coalitions is undeniably positive, in that all parties involved -- people with AIDS, the care/service providers, and federal funding agencies and programs -- realize clear benefits.

Coalitions improve the scope and volume of services available to **PWAs**, through better coordination, decreased duplication, and enhanced awareness of service needs and gaps. Coalition member agencies themselves improve their efficiency through the attendant cooperation and information-sharing. In turn, the agencies' often overstressed, overworked staff benefit from the supportive atmosphere and encouragement from peers fostered by a well-functioning coalition.

And, finally, federal priorities and programs are more effectively translated into meaningful action at the community level, when local groups are responsible for program application. The flexibility and expansion of services attained through coalitions not only reduces bureaucratic and administrative burdens on the federal agencies but also provides a ready source of information on conditions nationwide and a mechanism for rapid feedback.

In closing, **Chapter VI** summarizes the lessons learned about the operation of **HIV**-related coalitions and their relevance to as-yet-unforeseen challenges that the AIDS epidemic is likely to present in this country in coming years.

The first section of Chapter VI reviews eight characteristics or factors identified consistently by interviewees as critical influences on the effectiveness and functioning of HIV-related coalitions. They include: the uniqueness, both of the disease itself as well as of the people involved (either as patients or as care providers); the quality and fairness of coalition leaders; the inclusiveness and continuing evaluation of coalition membership; the **need** to maintain a client-centered focus; the adoption of a comprehensive social welfare model of service delivery (as opposed to a narrower medical model); and the need to maintain linkages with **PWAs**.

Two other issues, while cited often, elicit considerably less agreement, namely: the need for or use of established organizational structures and procedures and the role of private and public funding agencies. Each of the HIV service coalitions studied has developed its own structure and organizational culture, largely due to force of circumstance (i.e. there was little prior experience or expertise on which to draw.) While there is, so far, scant consensus about an ideal structure or the most effective operating procedures, it is likely that more attention will need to be paid to such issues if coalitions are to keep functioning effectively and sustainably in coming years. As regards the second point of contention -- while coalition members generally respect the role and constraints of funding agencies, they cite a need for more responsive or reasonable procedures (e.g. application time and criteria). While preferring independence from direct agency control, they also indicate a need for more "technical assistance" or guidance from the agency, especially **HRSA**.

Based on our firm conviction of the positive and beneficial impact of **HIV** service coalitions, Section 2 of Chapter VI offers four succinct recommendations aimed at enhancing these impacts: providing coalitions with technical assistance on organizational and programmatic issues; consistently disseminating and sharing information about coalition activities and concerns; providing much-needed financial support to cover coalition operating

costs (in **addition** to the customary program funding); and continuing to study and analyze these coalitions as they evolve, in order to better understand the issues and formulate plans for the future.

THE FORMATION AND OPERATION OF COALITIONS TO PROVIDE HEALTH CARE SERVICES TO PEOPLE WITH HIV ILLNESS

Analytic Synopsis

Final Draft

I. INTRODUCTION

As the incidence and magnitude of HIV-related disease and AIDS have multiplied during the 1980s, so, too, have the efforts to provide adequate and accessible care. But, as is well known, the needs appear to have far outrun the abilities of the medical, social services, and other care communities to manage on their own, prompting ongoing reassessments of existing approaches.

One of the more innovative responses to the problem of improving the quality, availability, and accessibility of the myriad of HIV-related services has been the adoption of a "coalition" approach. Under this system, groups and organizations involved in an array of sectors join forces to optimize the range and reach of their services in the context of limited resources (funding). Underlying objectives are to reduce duplication and/or wasteful competition among discrete services in favor of collaborative decisionmaking and multidimensional care.

This report summarizes the results of a study focusing on the intricacies of the development and operation of coalitions formed to facilitate the provision of health and related services to persons directly and indirectly affected with HIV disease and AIDS. The survey was conducted by a team of JSI staff members who collected information through an extensive literature review, in-depth site visits to four major metropolitan areas, and follow-up telephone interviews with care providers, patients, and policymakers across the United States, all during the latter half of 1991.

A. Research Methodology

The information on which this analysis is based was gained through the following means:

1. Literature Review: The study included a survey of theoretical literature on inter-organizational coalitions in general as well as on health-care and HIV/AIDS coalitions, though information on the latter is extremely limited. Unpublished documents developed for technical assistance purposes and abstracts from the International Conferences on AIDS constituted the major sources of information. Although neither provided an in-depth nor rigorous examination of the issues in HIV coalition development and operation, they did offer useful documentation of various

experiences with HIV-related coalitions.' The literature on coalitions formed to advocate for health care and social services in the 1980s also contains important practical information relevant to HIV-specific coalitions.

2. **Site Visits:** Researchers visited four cities -- Boston, Massachusetts; Dallas, Texas; Jersey City, New Jersey; and Seattle, Washington -- in August and September 1991 to collect in-depth information about the HIV coalitions in those communities. The cities had all participated in the HIV Service Demonstration Program funded by the Health Resources and Services Administration (HRSA) and, except for Boston, had also participated in the Robert Wood Johnson Foundation's AIDS demonstration. These four cities were selected in order to cover a diversity of patient populations and approaches. While all were considered to have developed strong coalitions around HIV/AIDS issues, the specific approaches to coalition development, the stages of development, and the perceived successes of the coalitions were quite distinct.

A protocol was developed to guide the site visits. Although the protocol was tailored for each visit, in all cases it included in-depth interviews with coalition leaders, members and PWA representatives; observation of coalition meetings and, where appropriate, client case conferences; and, review of written material such as minutes, procedural manuals, public information, and member descriptions. Interview questions were designed to elicit information on the major factors involved in creating, building, and maintaining a coalition; how the coalition formed linkages with people affected by AIDS; and, perceived accomplishments of coalitions in relation to HIV/AIDS service delivery. The information gained during the site visits underlies the bulk of the observations, analysis, and conclusions presented in this report.

3. **Telephone Interviews with Key Individuals:** Additional information was obtained through a series of telephone interviews with people directly or indirectly involved with HIV coalitions in cities that were not visited. This information largely reinforced the knowledge gained through the literature reviews and site visits.

B. Coalition Types and Characteristics

For the purposes of this report, the term "coalition" is used to refer to a group of agencies (and, occasionally, individuals) that have come together to enhance the provision of services for people directly or indirectly affected by HIV/AIDS in their community?

¹ See, for example: Peggy Stokes Nielson's Report on Allentown/Lehigh Valley AIDS Long-range Planning Coalition, prepared for NAIEP/CDC in 1991 and Fleishman et al, Organizing AIDS Service Consortia: Lead Agency Identity and Consortium Cohesion, Center for Gerontology and Health Care Research, Brown University.

² The terms consortium or federation **are** often used interchangeably and, while **we make** no distinction, we will **use** "coalition" throughout this paper.

The fields of political, organizational, and sociological studies offer a variety of useful tools for understanding the development and dynamics of coalitions. For instance, in much of the world, "coalition governments" are commonplace mechanisms for sharing power and resources in politically fragmented societies. Within the field of inter-organizational relationships (IR), coalitions are studied in the context of the nature and extent of interactions an organization has with a wide range of other organizations. And within sociology, coalitions may be viewed through the lens of community power structures, which can take many **forms**.³ While all these areas of inquiry provide a theoretical basis for understanding inter-group relations, there has been little systematic study of health coalitions, in particular those focusing on AIDS/HIV-related services. Hence, much of our current knowledge about HIV coalitions is based on the practical experiences of such groups, often subjectively interpreted by them.

Coalitions often evolve for purposes other than service provision, such as, for example, advocacy and political activism. In fact, political activity is an important unifying objective for coalitions and this type of coalition is prevalent in the health and social service fields. Among those focusing on HIV/AIDS issues at both the national and local level are the Boston AIDS Consortium or the Dallas Gay Alliance. The data shows that many cities have both service coalitions and advocacy coalitions which, while they often share the same membership, have very distinct missions and goals.

This overlap in membership and activities underscores an important aspect of coalition functioning: HIV/AIDS coalitions have found that it is usually essential to distinguish and separate coalitions according to their mission in order to ensure organizational survival and success. One of the few common themes emerging from the literature on coalitions is that common goals among members are important to a coalition's development and sustainability.⁴ When some members are concerned with broad social issues and social change and others are focused on specific tasks such as securing funding or improving a services, the coalition can experience difficulties.⁵

The need to distinguish advocacy from service was strongly reinforced by most of the coalitions surveyed in this study. While many of the coalitions' members (organizations and individuals) were politically active, their advocacy endeavors **generally** take place outside the framework of the service coalition.

³ See Shoshanna Sofaer, Coalitions and Public Health: A Program Manager's Guide, (Washington: Academy for Educational Development), 1992, for further introductory reading on **theoretical** frameworks of coalitions.

⁴ For discussion of goals, see Catherine Alter, "An Exploratory Study of Conflict and Coordination in **Interorganizational** Service Delivery Systems" in Academy of Management Journal, 1990, Vol. 33, No. 3, pp. 478-502.

⁵ See S.M. Rose. "Community organization: A survival strategy for community-based empowerment-oriented programs."

Since this study is based on HRSA demonstration sites, the coalitions' share a consistent focus on services. Other than this, however, they exhibit significant differences. The following is a brief summary of the characteristics of the four principal coalitions studied for this report:

1. Metropolitan Area HIV Services (MAHS), Boston

While Boston has several HIV-related coalitions, this study examined the coalition formed around the HRSA demonstration, known as the "**MAHS**" project. The Metropolitan Area HIV Services coalition was formed specifically to secure the HRSA demonstration grant and to maximize its impact once received. Boston was the only one of the four cities in the study which had not participated in the Robert Wood Johnson (**RWJ**) demonstration.

By design, the MAHS coalition membership was limited to agencies providing **HIV**-related services. While the HRSA demonstration was being funded, the coalition met monthly to discuss service delivery issues. Individual client cases were discussed at the meetings although these gatherings were not defined as case-management meetings. When the C.A.R.E. Act was funded, another coalition, the **Boston AIDS Consortium** (specifically, its Steering Committee) was selected to serve as the basis of the HIV Services Planning Council. Funding was not continued for the MAHS coalition, although many of the same agencies are represented on the Planning Council. MAHS ultimately disbanded.

2. AIDS Arms Network, Dallas

The AIDS Arms Network was formed in order to apply for Robert Wood Johnson funds. Housed initially in the Dallas Community Council, the coalition became organizationally independent as soon as it received sufficient funding to become financially independent. In contrast to other cities in this study, the AIDS Arms Network combines an active service role along with its functions as a coordinating body. This approach has led to some jealousy and fear of inappropriate competition among other AIDS service programs in Dallas that are seeking C.A.R.E. Act funds.

Weekly meetings of the AIDS Arms Network are centered around case management and service needs of individual persons with **AIDS(PWAs)**. The case-management services supplied by the Network help assure first-hand knowledge about the issues facing **PWAs**. These well-attended meetings have improved communication among member organizations and increased awareness of the services supplied by each agency as well as of service gaps that need to be filled. Not insignificantly, the meeting atmosphere also serves as a "support group" for overworked and often emotionally drained staff.

In contrast to the Network's case-management meetings, attendance at the HIV Services Planning Council meetings is meager. Absences are especially noticeable among members who were political appointees rather than being selected to serve on the Council for their history of AIDS-related efforts.

3. **Hudson County AIDS Consortium, Hudson County (Jersey City), New Jersey:**

This coalition was formed to apply for Robert Wood Johnson Foundation support. It was later expanded to respond to the HRSA Service Demonstration Project request for proposals (RFP). The third transition -- to a structure and membership required for the C.A.R.E. Act duties -- occurred in such a manner that it was barely noticed by most members. A subset of the coalition's members meets regularly for case management of individual **PWAs**; otherwise, there is no regular meeting schedule. At the call of the project director, however, coalition members have met to determine funding requirements, allocate grant funds, and plan for approaches to developing additional necessary services.

The Hudson County coalition is centered structurally and in terms of power at the County Health Department. Most members regard the project director of the grant, who is also Director of the Department, as the single most important source of enforced cooperation and collective beneficence. At the same time, however, members generally agree that major and minor decisions regarding the care for people with HIV/AIDS are made by consensus and collaborative agreements among members. The project director assures decisions are made by the group but does not dictate the outcome of decisions.

4. **Seattle - King County AIDS Care Consortium, Seattle, Washington:**

Seattle has the least structured coalition of all the cities contacted. While the formal coalition was formed in order to respond to the availability of Robert Wood Johnson and HRSA funds, functional cooperation and group decision-making have long been described as the "Seattle way of doing things." In fact, the Seattle coalition has never had a meeting of all its members at once. Subgroups of the coalition membership meet on an ad-hoc (both before and since receiving the funding) for case management, identifying and filling gaps in services, resolving conflicts among agencies, and coordinating care for **PWAs**.

Seattle has taken a "lead agency" approach to organizing the coalition, funneling grant money, and serving the AIDS-related needs of the community. For example, the Seattle-King County Department of Health, the community-based AIDS service organization (the North West AIDS Foundation - NWAF), and the people-of-color coalition (People of Color Against AIDS Network - **POCAAN**) have been designated as lead agencies for groups of related agencies and services. This approach has

reduced the amount of direct attention necessary from the Project Officer, and apparently works to the satisfaction of both funded agencies and their clients.

II. CREATING A COALITION

A. Impetus for Coalition Formation

Literature on management and organizational behavior often discusses the formation and existence of interorganizational relations (including coalitions) in terms of specific reasons and certain external conditions. One management expert takes a dual tack, linking both reasons and conditions in “a set of [six] critical contingencies of relationship formation”⁶ and defines these contingencies as:

- **Necessity** (the need to meet legal or regulatory requirements)
- **Asymmetry** (the potential to exercise power or control over another organization or its resources)
- **Reciprocity** (cooperation and collaboration in the interests of pursuing common or mutually beneficial goals or interests)
- **Efficiency** (internally oriented motives, prompted by an organizations desire to improve its input/output ratio)
- **Stability** (the desire to hedge against external/environmental uncertainty and achieve some measure of stability and dependability)
- **Legitimacy** (largely in response to pressures and expectations to appear in conformity with social or other norms and standards)

Judging from the results of our study, necessity, reciprocity, stability, and legitimacy all appeared to have some bearing on the formation of HIV service coalitions. Or in other (less academic) words, our study identified three principal reasons for which coalitions related to health and social services develop: 1) political activism and advocacy; 2) to take advantage of an opportunity; and 3) to unify against a potential threat.

That noted, it is very evident that the most compelling impetus, by far, for HIV and AIDS coalitions is the **opportunity to secure funding**. In all four cities studied, the requirement that a coalition be formed in order to receive funding for services was the critical factor leading to its existence. In cities receiving RWJ funding, the Foundation’s requirement that a coalition be in place prior to applying for funding provided the necessary catalyst for initial cooperation. Where RWJ funding was not received, the coalitions developed in response to the similar HRSA requirement. Even in communities with a strong

⁶ Christine Oliver, “Determinants of Interorganizational Relationships: Integration and Future Directions” in Academy of Management Review, 1990, Vol. 15, No. 2; pp. 241-265.

tradition of collaboration (such as Seattle), the impetus provided by the potential for funding was an essential element in stimulating the creation of the coalition. And, as communities that were not part of the original demonstration projects create coalitions in response to the requirements of the Ryan White C.A.R.E. Act, the prospects of obtaining funding will continue to be a significant impetus to coalition formation.

B. Factors Influencing Coalition Creation

It is clear that external stimuli (and particularly **financial** incentives) are powerful catalysts for the creation of HIV coalitions. However, external forces alone are not sufficient to create a coalition. And, while our findings cannot declare as “essential prerequisites” certain factors, we have identified several elements which facilitate the creation of a coalition.

1. Leadership

Foremost among these elements is the **presence and involvement of a leader** who is recognized as an impartial arbiter among competing demands for funds, services, and public recognition; who, as a team-builder, emphasizes coordination and collaboration among coalition member agencies; and who has an inclusive, open approach to membership and to all major coalition decisions.

When the leader is a public official, it also appears to be important that he or she be in a sufficiently high position to directly influence public policy, participate in the allocation of resources, and reinforce messages about the importance of the coalition’s efforts to the community. Interestingly, particular expertise in HIV/AIDS is not seen as an essential characteristic in those leaders cited as “effective.” What is stressed is the need for a listening approach and willingness to heed the advice of AIDS experts.

While coalitions do emerge without a recognized leader at the early creation stage, lack of clear leadership can lengthen the development time and may spawn confusion or ill-will that carries into future coalition efforts. As will be seen in the discussions in the next two chapters, a recognized leader remains an important element in the coalition after its creation, particularly through the building stage.

2. Experience and Technical Assistance

Communities accustomed to working through coalitions on other issues may **find** it easier to develop such groupings specifically for HIV services because the components and processes are widely understood. While interviewees in Seattle noted that they approached the organization of HIV services with a strong history of coalitions, other interviewees in general did not perceive past experience with

coalitions as essential.' Many felt that, with a recognized and strong leader, cities other than Seattle were able to create a well-functioning coalition.

At the same time, all the sites visited said that technical assistance would have been very helpful while they were creating and building their coalitions. None received any advice on issues such as optimal organization, membership, financial arrangements, or coalition functions. A few relied on contacts in other cities, especially San Francisco and Miami, for guidance.

Thus, at the very least, it appears that technical assistance can give developing coalitions a degree of confidence in major decisions, helping them move forward more rapidly with implementing their mission. More concretely, technical assistance can be useful during coalition creation by helping to identify the appropriate range of member organizations, develop the coalition structure, define decisionmaking and work processes, and facilitate resolution of disputes.

When providing technical assistance, however, it is important to remember that each coalition must be uniquely fashioned according to the nature and needs of the community it is serving. A generally effective approach is to build upon existing leadership, interagency relationships, and decisionmaking processes. There is no single "right way" to create an HIV coalition.

3. **Other supportive factors**

One of the most often-cited factors supporting **the** development of HIV coalitions is the "compelling" nature of AIDS work and the "special quality" of the individuals involved. Because of the crisis level of need and the compassion, commitment, and sacrifice of those involved (especially in the early stages of the epidemic in a community), people are often able to set aside personal agendas and issues in order to work for the "greater good." The direct involvement of **PWAs** in coalition formation and development serves to remind the members of their mission and minimize competition.

Other factors include: the involvement of respected spokespersons, either from the public or private sector, who are highly visible in helping to form and support the coalition; the participation of all existing AIDS-relevant **health** and social service agencies so that the smallest number of new agencies are required to be formed; and a strong, visible, and vocal gay community which has a **political** base that is used to support the coalition effort.

⁷ It is interesting to note that the Nielson report on the Allentown coalition finds "pre-existing community efforts in HIV/AIDS education, prevention, and/or services" to be an "essential component" for the coalitions success (p. 7).

4. Barriers to Coalition Formation

All communities experience problems when creating a new coalition. The successful coalitions are those that transform these problems into challenges and team-building exercises, often emerging stronger as a result. The most frequent problems encountered include: turf issues (e.g., white vs. people of color, gay men vs. women, public education/prevention vs. service delivery) which can threaten to take precedence over the needs of people with AIDS; political battles over leadership; attempts at dominations by a few providers or agencies; exclusion of important groups from the coalition by other members; and homophobia and/or AIDS-phobia discouraging appropriate groups from participating. A recent problem -- one that is rarely observed in the early, voluntarily-formed coalitions -- is apathy and absenteeism of members appointed to the HIV Services Planning Council for political reasons.

III. BUILDING A COALITION

Once a coalition has been created, members must embark on the challenging process of building it into an entity that works effectively toward achieving objectives. A helpful first step is to develop some consensus on the coalition's mission and **goals**. Next steps may include defining its organizational and administrative structure; pursuing an expansion of membership and ongoing clarification of members' roles; and developing operating policies and procedures.

However, in the coalitions studied, such building or developmental efforts have rarely taken place in a pre-planned or formalized series of activities. Often, the processes and changes were rarely even recognized explicitly by the people involved. Nevertheless, over time, most coalitions do go through these phases.

A. Mission and Goals

1. The primary **mission** of all the HIV/AIDS coalitions observed in the study is the enhancement of services to people with HIV disease. Service enhancement is a **two-pronged** issue: It includes expanding access to existing services as **well** as developing new services to meet the needs of **PWAs**, their families, and friends; and it includes coordinating existing services through some joint approach to patient-centered communication, cooperation and case management. **Generally**, the coalitions embrace a comprehensive service delivery model including a full array of psycho-social and daily living services as well as health care, rather than a more focused medical model. This is viewed by all concerned as a very positive aspect of the **HIV service** coalitions.

AIDS prevention and public education, although central to the mission of some individual member agencies, are not a primary focus of the coalitions. Similarly, political activism and advocacy are undertaken by some of the member organizations but are not central to most coalition missions. With the advent of the C.A.R.E. Act, planning became the responsibility of the HIV Planning Council in Title I cities. Where an already established coalition took on the role of the Planning Council, it has assumed this function.

2. According to our survey evidence, the **primary goal** of all the coalitions is to secure additional funding for services.⁸ Coalitions were dedicated to improving access to and quality of AIDS care and could articulate these goals, they saw increased funding as the *means* to achieve those goals. While the effort to secure funds is the impetus for creating the coalitions, the level of success in doing so can be viewed as the essential glue holding the coalition together during the building stage.'

B. Organizational Structure

Occasionally, a coalition's organizational structure is explicitly defined during the creation stage. More often than not, the structure evolves and only gradually becomes explicit.

Designating an individual or agency as leader appears to be a critical first step in developing the coalition's structure. If the leader is recognized as an unbiased team-builder, the structure develops relatively smoothly. Committees are formed, work assignments made, member roles defined, and meetings scheduled as specific issues and/or needs arise. Rather than being a weakness in HIV-service coalitions, this somewhat loose approach to organization can be a strength when combined with a respected leader. It is likely that a rigid organizational structure at the outset might exacerbate turf issues. More important, a loose organizational structure allows flexibility in responding to the many unexpected issues that confront the coalition in its early stages.

Thus, while it is important to define a leader as early as possible in the development of a coalition, it is preferable not to start with a rigidly defined organizational structure, but rather to allow it to evolve during the building phase.

C. Membership

A coalition's inclusiveness varies in terms of the range of organizations represented and in the roles each coalition member plays. On one hand, coalitions may limit membership only to agencies receiving funds through the coalition; on the other, they may include all

⁸ See the discussion on Boston coalition in Sec. 5.1 for the importance of **success in securing funding**.

health and social service agencies involved in or interested in HIV/AIDS issues. Predictably, most fall somewhere in between.

There are three principal types of members in HIV service coalitions:

1. **Active service providers** providing specific health care or social services to HIV clients and usually participating in coalition case-management efforts. The responsibility of these members is to assure that their specific services are as accessible and acceptable to as many targeted people as is possible.
2. **Public agencies** with legislative, regulatory, or financing authority. The responsibility of these members is to facilitate the provision of services through enabling legislation and regulations, through the removal of bureaucratic barriers to care and through locally enhanced financing of services. Public agencies may also be service providers and participate in such coalition activities.
3. **Constituency groups** providing input to the service and regulatory groups in the coalition. The responsibility of these members is to represent the needs of targeted clients.

Based on our observations, the most effective coalitions appear to be those whose membership is as inclusive as possible and which utilize members' organizational structures and operational procedures to assure efficient operation. That means an effective coalition includes: service providers who address the full range of health care and social service needs of people with or at risk of HIV/AIDS; public agencies dealing with health, mental health, substance abuse, social service, housing, and reimbursement; and advocates for affected and at-risk groups.

Because such an inclusive approach leads to a very large coalition (70+ agencies in the Broward County (Ft. Lauderdale), Florida HIV/AIDS coalition), it is necessary to use some organizational structure such as specially focused work groups (e.g., on case management) and standing ad hoc committees (e.g., task force to create treatment protocols for mental health care) to effectively manage work. Such structures also offer a way to involve relevant organizations that are not members of the coalition.

Although coalitions should generally be as inclusive as possible, forced membership does not work. Several of the coalitions had some groups drop out and other groups which, despite active recruitment, chose not to join. The essential point is that the coalition be perceived as open and that the decision to participate rest with individual agencies. None of the coalitions visited have faced the difficult prospect of removing a member for any cause, although this possibility should be foreseen in the coalition's bylaws.

D. Operating Procedures

In order for an inclusive coalition to function effectively, there must not only be a structure but also commonly understood operating procedures. Neither the structure nor the procedures need be complicated or even documented; often, they facilitate coalition functioning when they are relatively flexible.

Established procedures are most often found in relation to the following functions: case management, grant applications and funding allocations, planning, committees and task forces, and all-member meetings. Procedures were rarely in place to address adding or removing members or for evaluating the performance of funded agencies. Anticipating future funding constraints and/or differing levels of performance among their members, the coalitions themselves have expressed the need for knowledge and implementation of procedures related to evaluation of services. In fact, this was the most frequently requested area of technical assistance.

E. Major Supportive Factors in Building a Coalition

1. Among the factors that facilitate the building of a coalition, the primary one is success in achieving coalition goals, which in most cases, means funding for services.

In this regard, the history of coalition efforts in **Boston** is instructive: Coalition development efforts were first mounted to apply for RWJ Foundation funds. When **those** were not received, the coalition essentially disbanded. However, it was later **rejuvenated** in order to apply for HRSA funds. And, members note, it was easier to develop the coalition for the HRSA grant because they had come to know each other during the earlier effort. Furthermore, each coalition in the other three cities emphasized that the initial process of forming the coalition (for the RWJ application) would have resulted in better use and coordination of services even if no funding had been secured.

This said, it must be noted, however, that service-oriented. coalitions are unlikely to progress through the building stage without concrete success in achieving their goal of enhancing services (i.e. getting additional money). Thus, a significant question remains unanswered: What will happen to the coalition when funding becomes stable or decreases? Seattle offers an encouraging sign: When it experienced a decrease in total HN-related federal funds as a result of the C.A.R.E. Act allocations, the members rallied to joint decision-making about budget cuts, and there were no noticeable problems within the coalition itself.

2. A second critical factor in successfully building an HIV service coalition is the group's ability to maintain a client focus. In other words, coalition development benefits from a focus on the needs of people with **HIV/AIDS** and responding to those

needs -- rather than a focus on the issues and agendas of individual coalition members.

Maintaining the client focus is facilitated by:

- The presence of a respected, unbiased coalition leader.
 - Regular member participation in case-management meetings where the needs of individual clients are discussed.
 - The recognition among coalition leaders and members of the real demographics of the epidemic in their community (i.e. neither de-emphasizing the service needs of “unpopular” client groups such as intravenous drug users or gay men nor over-emphasizing the needs and numbers of other groups).
3. Time is also a supporting factor in the development of coalitions. Communities which started developing their coalition in preparation for receiving an RWJ grant speak very positively about their experiences. They had approximately four months to build and define organizational structure and operations prior to applying for funds (i.e., four months between issuance of the RFP and its due date). On the other hand, a great deal of frustration is voiced about coalitions formed for HRSA or C.A.R.E. Act funds, when decisions and funding allocations had to be made within a matter of **weeks**.
4. Financial support for coalition staff and activities also facilitates development, especially when the lead coalition agency is a private agency operating on limited funds. Most coalitions observed did not have a special staff to manage the coalition during the building phase; most relied on staff and resources of member agencies. In all cities, financial support from RWJ, HRSA and/or state agencies was critical in supporting the member agencies’ coalition involvement. In general, public agencies were better able to contribute to the coalition without outside funding, thereby assuming a high-level position and commitment to the effort.

The fact that many coalitions have developed without specific funding (or even technical assistance) for their activities is a credit to the dedication and commitment of those participating. But such an approach is neither sustainable over the long term nor desirable as the size and complexity of coalitions grow. Long-term support of coalition functions is a significant future challenge.

F. Barriers to Coalition Building

The low level or lack of the supportive factors discussed above constitute serious barriers to coalition growth and development. For example, coalition development is impeded

when there is no concrete success which rewards participation; when special interests take precedence over client needs; when no clear leader emerges or leadership fails; or when a few individuals or agencies assume the full burden of coalition organization and activities.

In addition, the development of service oriented coalitions may be hampered if the coalition becomes actively involved in policy development or political activism. There are two reasons for this. First, members have limited time, energy and resources to devote to coalition efforts, most have other full time responsibilities. To the extent the experts are channeled into formulating defining positions or policies, members have less to apply to addressing complex service delivery problems. Second, members often disagree on policy and political issues (all coalitions visited acknowledged this). Calling attention to these differences through political debate can make it difficult for the same groups to work objectively and collaboratively around service delivery issues. While political activities are viable and important functions for coalitions, most service coalitions feel that undertaking policy-related functions **significantly** detracts from their service mission.

IV. MAINTAINING A COALITION

Most HIV service coalitions contacted for this study are either in the creation or building phase. While a few have reached the maintenance phase, it is too early to draw definitive conclusions from their experiences. Available literature, too, offers few specific assertions about maintenance of service coalitions. From our interviews and observations, however, we can offer some general comments and highlight issues that may bear watching as more coalitions move into the maintenance phase.

A. Differential Impact of the Ryan White C.A.R.E. Act

Some of the HIV service coalitions started three-to-five years ago (for RWJ or HRSA funding) were entering a maintenance phase when the Ryan White C.A.R.E. Act was implemented in 1991. The effect of the C.A.R.E. Act on coalition efforts ranged from minimal to extreme, although for all it forced some regrouping and a return, albeit temporarily, to the building phase.

The C. A.R.E. Act had the least impact in non-Title I communities which continued to receive essentially level funding for services through Title II. Impact was also fairly low in Title I cities where the demonstration consortium took on the role of the HIV Services Planning Council. Some changes in membership and functions were required, but the overall mission and goals remained intact.

Where the C.A.R.E. Act had the most impact was in Title I cities where the coalition put in place for the HRSA demonstration program was not a significant player in the new HIV Services Planning Council. In other words, a new group of individuals and agencies took over many functions of the HRSA coalition. For instance, **in one** case (Boston), the

previous HRSA Service Demonstration Project coalition ceased to exist. In another (Broward County) the change left the HRSA coalition without one of its main goals and the community with more than one service coalition. While the long-term effects of forming a new coalition (Planning Council) remain to be seen, there is already a sense of competition rather than collaboration in some of these communities.

Significant effects of the C.A.R.E. Act are also anticipated in cities which do not receive Title I funds and which will not receive funding from their state at a level commensurate with their HRSA funding (e.g. Denver). These coalitions will have to quickly address the commensurate challenges, including increased competition among members for limited funds and the establishment of appropriate procedures for allocating and evaluating funding of services through the **RFP process**.

B. Coalition Evolution During the Maintenance Phase

In the maintenance phase of development, coalitions focus on institutionalizing the goals, structure, and procedures that were evolved during the building phase. In fact, a remarkable adherence to original missions and goals was observable. Nevertheless, the maintenance phase is not entirely static. Changes do (and, in our view, should) continue to occur as target groups expand, incidence increases, and the intensity and scope of medical and social services grows. The literature reviewed highlights continuing flexibility in coalition structure and membership as important elements for continued effectiveness.

The addition of new members appears to be the major change in coalitions as they enter the maintenance phase. In most instances, these additions are positive, resulting in a broader scope of services and in more at-risk groups being represented. Occasionally, the impact is negative as when political appointees named to the HIV Services Planning Council rarely attend or when multiple groups vying for funding demand an equal voice regardless of the relative incidence among the populations served.

Despite the difficulties that occur when new organizations and constituencies are brought into an existing structure, the continuing evolution of membership to match the services to the populations needing them helps the HIV coalitions maintain their client focus and an appropriate range of service delivery programs.

Although observed in only one instance in our study, a change in leadership style and functions during the maintenance phase appears to be another evolutionary step that coalitions should anticipate. In the maintenance phase, leadership may have to exert more direct control, guiding the group through difficult decisions, acting as a catalyst for change, and, at the same time, allowing member agencies greater freedom to develop new programs. **As the** HIV-related services become more institutionalized, there is less need to focus on the **team-**building that is so important during the creation and building phases. Leading an HIV service coalition requires immense time and energy, and leader burn-out should be expected.

While a change in leadership is by no means required as the coalition moves from one phase to the next, neither is it a sign of problems.

C. Supporting Factors in Coalition Maintenance

1. Leadership continues to be critical in the maintenance phase. ~~o v e r~~ i s likely and even beneficial, it is important that leaders continue to be viewed as strong and impartial and that the leadership is exerted by individuals holding relatively high responsibility in their agencies. Certainly, the leader should be someone capable of piloting the coalition through difficult and even unpopular decisions.
2. Continued benefit from participation is important to coalition members. Thus, while needs may exceed available funding, member groups must feel that they have improved access to funds that are more rationally distributed than if each agency were to apply on its own. Similarly, they need to feel that the quality of their client services are improving as a result of continued participation in the coalition.
3. Because all HIV service coalitions will reach a point when members' needs for funds exceed the availability of target funds, coalitions need to establish objective funding and program evaluation procedures to distribute C. A.R.E. Act funds and to determine that funds are being used wisely. Appropriate procedures will help mute interorganizational conflicts and possible disintegration.

D. Barriers to Coalition Maintenance

There is some indication that when the lead agency itself provides services and receives coalition funds to do so, it is difficult to retain impartiality. Whether perceived or real, such conflict of interest may spawn distrust among other coalition members. On the other hand, it may be that a concomitant service role makes the lead agency more "in touch" with the realities and constraints of service delivery.

Changing missions or goals at the maintenance stage sometimes dissipates coalition energies and focus. This is evident for major changes (e.g. a shift from service to political advocacy) as well as for apparently minor shifts in, say, the demands of the funding agencies. For example, early changes in the focus of the HRSA demonstration programs and the advent of the C.A.R.E. Act caused some turmoil. While everyone realizes that change is inevitable over a period and that flexibility is important, the potential benefits of policy change need to be weighed against the organizational or functional effects on the coalition.

V. IMPACT AND ACCOMPLISHMENTS OF COALITIONS

There is universal agreement among members of HIV service coalitions that a coalition approach improves HIV-related services. Our observations strongly support this view. Although there are still significant access problems for somePWAs as well as gaps in critical services, the situation in communities with service coalitions is far better than if no coalition had been formed. Improved coordination is an oft-mentioned achievement of coalitions.

Furthermore, despite inevitable turf and political battles and participation issues, HIV service coalitions have broken through many long-standing barriers to cooperation and service integration. Specific accomplishments of coalitions benefit both the participating agencies and, most importantly, the people directly and indirectly affected by HIV/AIDS.

A. Impact on Clients

Coalitions have improved both the quantity and quality of services for people with HIV disease. Specific accomplishments include:

1. Increase in the scope and volume of services available to people with HIV/AIDS. Through case-management and other meetings, AIDS coalitions have been able to identify and help eliminate gaps in services. Adoption of a comprehensive approach to service delivery has led to expanded medical care as well as expansion of important personal services such as housing and food distribution. The improvements have been achieved both when starting or expanding services with coalition funding and by leveraging existing services and making them more accessible.
2. Improved coordination of patient care. Given the multitude of services required for someone with AIDS, coordination of care is seen as a particularly important and beneficial achievement. According to one theorist, coordination helps organizations "increase their ability... to solve problems that no single organization acting alone could solve."⁹ In the case of HIV service coalitions, coordination occurs at two levels -- among agency staff at the client level (through case-management sessions) and among agency leaders at the administrative level. Such coordination results not only in the patient having to expend less time, energy and resources to get services but also in better communication among the various service providers about the care being provided.

⁹ See Alter, pp. 483-485.

3. Decreased duplication of services. The coalition helps member agencies become familiar with each other's capabilities and approach to service delivery. The trust that is generated helps coalition members to avoid establishing duplicative and competing services. Duplication of effort is still a problem in many areas, especially where similar services are set up for different risk groups and a degree of trust has not been reached among the "competing" organizations. In some cases, coalition members are aware of the multiple services and have made either an implicit or explicit decision that the multiple services are acceptable for the present because to eliminate the duplication would disrupt historic care patterns or cause disruption of the coalition.
4. Enhanced agency awareness of the needs of PWAs. Most HIV service coalitions include constituency groups in their membership and all have PWAs on the staff of some member agencies. The PWA representatives on the coalitions under study were uniform in their belief that service delivery was improved by the coalitions' increased attention to the actual and multiple service needs of people with HIV/AIDS.
5. Improved quality of care. As services are increased, better targeted and coordinated, and as communication among providers is improved, the quality of care for people with HIV and AIDS improves substantially. In addition, involvement in a coalition and its deliberations builds in a level of accountability into the system. Without being prescribed, a peer review process essentially takes place, as it quickly becomes apparent when a provider is not adequately meeting patient needs.

B. Impact on Coalition Member Agencies

In addition to the advantages for patient care, coalitions have numerous positive impacts (beyond securing funding) on member agencies and their staff. These include:

1. Promoting. Social and health service agencies and community groups which, for years, have existed in isolation now voluntarily work together. Much useful information learned about HIV clients is transferable to other clients, which helps maximize service impact. And, as interagency trust grows, it is more likely that service delivery problems will be anticipated and prevented -- a welcome move away from the crisis-based response system that characterized the early years of the AIDS epidemic.
2. Acting as a support group for service/care providers. Working in HIV/AIDS is extremely stressful and burn-out among providers is high. Participation in a coalition often provides important support for agency staff. By meeting with their peers on a regular basis, they feel less isolated, they can talk frankly about their frustrations, even engaging in the dark humor that is so rarely understood outside the HIV/AIDS world. More positively, they see that they are not alone in attempting to provide services and their jobs are made significantly more tolerable and rewarding.

3. Sharing data and information. The potential for sharing both individual client-level and program-level data is just beginning to be recognized by the HIV service coalitions. Earlier concerns about maintaining absolute patient confidentiality and the security of agency information have given way to a recognition of the benefit of pooling information and thus avoiding duplication or service gaps. Several coalitions are installing automated case-management systems to consolidate information about patient needs, program eligibility requirements, etc. Such information-sharing has the additional benefit -- currently appreciated most by HRSA -- of providing a rich data base on which to base future analyses and studies of HIV services.

C. Impact on Implementation of Federal Programs

The coalition members interviewed gave details of how each community was managing its AIDS epidemic by local action financed, at least in part, by federal funds. The benefits of adopting a coalition approach to securing and/or managing federal funding include:

1. Appropriate allocation of federal funds in a way that matches local needs for support and service delivery. In using the primary grants, coalition members feel that they are able to spend the funds more rationally than would have been possible if decisions were made and implemented nation-wide without regard for local differences.
2. Effective translation of federal priorities into meaningful community-based services. While not all coalition members have a firm understanding of the scope and details of HRSA policies and C.A.R.E. Act provisions, each coalition leader has kept these issues at the core of coalition deliberations. The programmatic flexibility achieved through direct federal funding of the coalition, and its indirect funding of service programs, is clearly appreciated. (There is, however, an accompanying concern in some coalitions that local RFP processes are flawed or less than fair -- an issue that needs to be addressed.)
3. Providing a mechanism for feedback to HRSA on the application of federal HIV-related programs and policies. The efficacy of most client-directed federal AIDS programs can only be measured at the community level, but such evaluations must typically wait several years before being carried out. The existence and structure of coalitions is such that it facilitates the almost immediate transfer of important information to HRSA program managers about the impact of federal programs at the local level. Developing common definitions of types of services and compatible data collection formats will improve the usefulness of this feedback loop.

In summary, HIV service coalitions are widely perceived to be beneficial for both people with HIV/AIDS and for the agencies and groups that participate in the coalitions. The development of new coalitions under the Ryan White C.A.R.E. Act can spread these

benefits to many additional communities. Continued support of the coalition approach will result in enhanced scope, quality, efficiency and effectiveness of HIV/AIDS services.

VI. FACING THE FUTURE: RECURRING THEMES AND RECOMMENDATIONS

A great deal has been learned about the creation and development of HIV service coalitions through the initial efforts of the Robert Wood Johnson Foundation (RWJ) and the Health Resources and Services Administration (HRSA). While many are still in early stages of development, the lessons learned so far by existing coalitions can be successfully applied to the many other communities which are just now starting coalitions under the Ryan White C.A.R.E. Act.

However, while this paper has synthesized many of these lessons, it is daunting to try and predict what might happen as the epidemic expands and the coalitions mature. From our current vantage point, the future looks very uncertain. Perhaps the **only** statement that can be made with any certainty is that it will become increasingly difficult to sustain HIV service coalitions for a number of reasons. For instance, to a significant degree, the early successes of HIV service coalitions have been due to the commitment and energy of dedicated individuals and agencies in areas seriously affected by the epidemic. As the epidemic expands and new groups become involved, and as both funds and people become exhausted, such intense dedication will be difficult to sustain.

In many cases, such vulnerability will be compounded by the fact that the new groups¹⁰ which need to be drawn into the coalitions have little history of coordinating with programs organized for the clients of the first wave of the epidemic (namely, gay men). Communicating with and responding to these new client groups can be very difficult for the established AIDS organizations especially as many communities lack organizational representation of such groups.

It is almost certain that demands for HIV-related services will increase without commensurate increases in funding. This will confront coalitions with complex resource allocation decisions that are likely to pit members against each other. While a strong **client-**focused approach and objective procedures for making funding **allocations** can help mitigate potential disputes, there will be situations when even deserving programs might have to face cuts. Can **coalition** dissatisfaction and member demoralization be avoided?

According to participants, HIV service coalitions have demonstrated the significance of their role in the delivery of HIV care -- for the client, for the service providers, and for the funding agencies. The challenge for the future is to adapt to financial and political threats

¹⁰ For example, constituency groups representing minority populations or agencies **addressing substance abuse issues**, etc.

to survival so that the coalitions can continue to contribute effectively to the care of people affected by HIV and AIDS.

A. Recurring Themes

Before going on to the survey group's final recommendations, it would be useful to reiterate several themes that emerged from the literature review and site visits. The commonality of these issues and their prevalence help provide the basis for our appraisal of achievements and recommendations made in the last section of this chapter. In brief, they are:

1. Nature of the Dii

Two phrases are heard repeatedly when people are asked what is that makes **HIV**-service coalitions work. The first is "the compelling nature of AIDS," referring to the size of the epidemic, the system's inability to meet the demands, and the heart-wrenching individual stories that abound. The second is "the quality of people who work in AIDS," referring to individuals' indomitable spirit, personal sacrifices, and level of devotion that far exceeds mere professional requirements. Combined, these elements are seen as significant factors motivating people with differing points of view and agency agendas to seek effective collaboration.

2. Leadership

As is clear by now, leadership is key in all phases of coalition development, especially during the building phase when the coalition's structure, membership, and operating procedures are taking form. The characteristics that seem to consistently contribute to effective coalition leadership include a team-building spirit that elicits coordination and collaboration from members, awareness of AIDS-related service delivery issues in the community, and mutual support between coalition members and the leader.

Other important characteristics include: an open, inclusive approach to membership; the ability to listen and integrate many different perspectives; perceived impartiality both in terms of advancing his/her own agenda and in balancing other members' agendas; and the **willingness** to "take charge" when necessary for difficult decisions. It is also seen as very helpful if the leader is in a high-level, high-profile position.

3. Client-centered Approach

Focusing on client needs rather than agency or organizational issues helps minimize turf conflicts and optimize the use of limited resources. There are two ways a coalition maintains its focus on clients:

- Basing coalition-funded services on the actual demographics of the HIV/AIDS population in the community. For instance, in cities where adult, white gay men constitute the vast majority of **PWAs**, overemphasis on the needs of children with AIDS may be counterproductive in terms of the perceptions it creates. Similarly, in communities experiencing significant incidence among I-V drug users and their partners, domination of the coalition by gay activists is not productive.
- Basing services on the actual needs of clients. In the preceding examples, programs for HIV-infected women must address family-planning needs instead of pushing unrealistic programs that insist on abstinence.

Emphasizing the actual demographics and service needs in a community promotes an *esprit de corps* among coalition members, especially when difficult choices must be made if the group is going to target sometimes “unpopular” clients and face down political pressures to serve only “innocent victims.” This can be greatly facilitated if the coalition relies on objective needs assessment and client-centered data systems. At the time of this study, however, such systems were in their infancy.

Case-management meetings attended by representatives of HIV-related service agencies also seem to be an important way for coalitions to maintain their client focus. While the needs of relatively few clients can be addressed in the typical one-hour-per-week meetings, they serve to raise specific service issues and force members to address them in a concrete way. The meetings also increase coalition members’ understanding about the contribution each agency makes to the service delivery system. Such meetings also serve as support groups for overly stressed service providers who need to hear appreciation from their peers. Despite some early concerns, client privacy issues have not generally surfaced as a result of *these case* management meetings as long as due attention to client confidentiality is maintained.

4. Model of Service **Delivery**

In order to maintain the client focus, coalition members stress that it is important to use a comprehensive “social welfare” model rather than a more narrowly focused “medical model” in defining, organizing and delivering AIDS-related **services**.¹¹ This broader model was delineated most specifically by our Seattle interviewees who said it includes: patient education, prevention, behavior change, counseling, housing and social services, income maintenance, patient advocacy, and a fundamental

¹¹ While respondents in this study stressed the comprehensive coalition mode, there have also been instances where such a broad approach is plagued by misperceptions and distrust. Specifically, **Fleishman et al** note the strains in the ‘interface’ between **medical/hospital** staff and community-based workers (pp. 22-24.)

understanding that medical care is only one of the many services needed by people with HIV. The concept was termed a “public health approach” and defined as following the “classic model for delivery of **STD** services. ”

Coalition members in several cities emphasized that HIV services should not be dominated by or case-managed through physicians -- as these professionals are too busy, under too much pressure to manage physical illnesses, and not trained to respond to the full range of biological, psychological and social issues facing **PWAs**.

5. Inclusiveness of Membership

Ideally, coalitions should include representatives from all groups who are, or likely to soon be, affected by AIDS. However, in a general comment on health coalitions, one author notes that “Coalitions may limit their membership initially in order to get things off the ground. . . . New members can be added as the coalitions develops, because of a recognition that a particular sector or organization is a **keyplayer**.”¹²

In most cases in this study, the membership has continued to evolve once the coalition is established and functioning. While an increased membership poses challenges to organizational structure and consensus, the issue can be resolved by using committees and working groups based on commonality of services and dedicated to improvement and integration of service delivery. Communication procedures for the subgroups and coalition as a whole must also be developed.

6. Coalition Structure and Operation

While there is agreement that the coalition approach is the best way to plan and deliver HIV/AIDS services, there is very little agreement about an ideal structure or the most effective operating procedures. Each of the coalitions studied has developed its own structure and organizational culture, since no guidance was available at the stage of coalition definition. Being created in order to qualify for RWJ or HRSA funding, most coalitions were primarily concerned with that function rather than with developing an elegant organizational structure. In fact, many interviewees averred that there is no “structure” for their coalition, and that it still functions only as a loose collection of groups that have come together on paper to qualify for federal and state funds.

While some coalitions hold regular, full meetings (even those with more than 50 member organizations), others meet only in small working groups and committees, and communicate primarily through the coalition director. Case-management meetings seem to be one mechanism used consistently by most coalitions, and are seen as

¹² Sofaer, p. 16.

helping improve client services, build trust among coalition members, and support provider staff.

7. **Role of People with HIV/AIDS**

The linkages that all HIV service coalitions have with **PWAs** are of two main types:

- Through inclusion of one or more formal organizations of **PWAs** in the coalition
- Through member agencies that have **PWAs** on their staffs and representing them in coalition functions.

Coalition members contacted say that the inclusion of people directly affected by AIDS is essential, and helps keep the coalition focused on the needs of the clients. There is one caveat to this, however. Most agree that it is better to have **PWAs** involved as representatives of groups rather than in their individual capacity. This is because individual views and experiences of the service delivery system may be skewed according to income, race, sex, risk group, age, or stage of illness, among other factors.

This expressed need for increased, formal PWA input appears to be as much philosophical as practical in origin and is based on the view that such representation will help keep the coalition "honest." What is seen as most needed is input from individuals and groups knowledgeable about the practical aspects of HIV-related service delivery and about the problems and experiences of **PWAs** as recipients of those services. The need for combined **PWA/service** expertise was most emphatically stressed as necessary in developing the and reviewing subsequent proposals for C.A.R.E. Act funds.

8. **Role of Funding Agencies**

Both private and public funding agencies are generally respected by the HIV service coalitions. The Robert Wood Johnson Foundation is particularly applauded for the four-month lead time it allowed for developing demonstration applications. A typical comment was that AIDS services in the community would have been improved even if the RWJ grant had not been received -- because of all the coordination that went on during development of the proposals.

In contrast, the coalition members expressed concern about the short time-frame for developing HRSA proposals and responding to new requirements of the C. A.R.E. Act. But they also feel HRSA staff have been quite supportive of their efforts and understanding about community differences and service constraints.

The coalitions uniformly feel that HRSA could be more useful in providing technical assistance. While Project Officers were consistently praised for their support of coalition efforts, interviewees noted the lack of experience in AIDS-related service delivery among HRSA staff, and viewed this as a serious limitation.

The coalition members were particularly interested in technical assistance with developing **RFPs**, allocating funds, assessing and awarding contracts, establishing a valid system for responding to challenges of the coalition's review committee, and evaluating the efficacy of their funding decisions. There was also a felt need for technical assistance from their peers about program strategies and successes among different coalitions. To this end, they feel HRSA site visits should include people who can provide expert consultation as well as program oversight, which has been the emphasis in the past.

The effect of the Ryan White C.A.R.E. Act was different in each community studied -- ranging from minimal in non-Title I cities where funding remained stable, to extensive in Title I cities where a new coalition was formed to manage C.A.R.E. Act funds. At the time of the site visits (only a few months **after** the implementation of the law) many of the coalition members had only a very basic understanding of the practical, financial and legal implications of the legislation and viewed it simply as a "new pot of money." Most of the impact of the law on the coalitions, both positive and negative, is still to be felt.

B. Recommendations

This study strongly supports the continuing development and support for community coalitions designed to improve services for people infected and affected by HIV and AIDS. Following are several specific recommendations offered with the intent of strengthening the viability and potential for continued success

1. Make technical assistance available to both **developing** and established coalitions. Several areas of needed technical assistance emerged during this study, foremost in procedures for awarding funds to coalition members and in evaluating member performance. Such aid will help newly formed coalitions move quickly into their service functions, and are essential for established coalitions facing shrinking sources of funds.

While rarely mentioned explicitly by interviewees, a much-needed area of technical expertise and assistance appears to be in conducting rapid and accurate "needs assessments." Coalitions as a whole, as well as individual member agencies, must recognize the importance of investigating and identifying the extent of needs and resources if they are to design and implement responsive and effective service programs. Corresponding to the needs assessment, coalition members must be able to reliably report on their accomplishments.

Technical assistance in data systems and data analysis is essential. Technical assistance is frequently requested in effective organization methods -- to actively involve constituency groups in coalition activities. Many communities have experienced problems involving groups representing racial/ethnic minorities, often because no such groups exist.

Assistance with formulating rational membership and operational structures is also needed, especially among developing coalitions. In more developed coalitions, technical assistance may be needed to create a system for resolving member disputes. Because all communities and coalitions are different, the most useful technical assistance will be one-to-one, through site visits and consultation. In all cases, technical assistance must take account of the unique characteristics of the community.

2. Disseminate information about coalitions. It is essential that a wide variety of inclusive mechanisms be set up to promote information-sharing and dissemination. Regularly scheduled meetings for coalition members or sub-committees, occasional interactions with the media and public in cities, exchange visits among coalitions members in different regions, the organizing of occasional seminars and retreats, and the documentation and publication of experiences and observations are some elementary methods. It is crucial that individual coalitions and groups of coalitions develop some sort of "institutional memory" -- in terms of a documentation center containing papers, abstracts, reports, etc. where the material can be easily accessed by interested groups.
3. Assure that coalitions receive the financial support they need to survive. HIV service coalitions exist largely because a few individuals and agencies have devoted substantial energy and resources to their creation. They continue to operate without much direct funding, relying on the voluntary contribution of staff and resources from member agencies. While it may seem inappropriate to designate a percentage of needed service dollars for "administrative costs," the long-term survival of coalitions calls for exactly such funding. Since coalitions have demonstrated their effectiveness in **improving and** stretching services, such an investment by federal and state governments is justified.
4. Continue to observe and analyze coalitions as they develop and mature. There is still much to be learned about the effective use of coalitions in HIV service delivery, especially about maintaining coalitions through changes in the nature and extent of the epidemic and consequent expansion of service delivery to a more diverse client population. Because there is no precedent for such an effort, it will be particularly important to consistently observe the development of coalitions, deduce the important lessons that can be transferred to other coalitions, define technical assistance needs, and revise laws and policies.

BIBLIOGRAPHY

(Including cited and suggested readings)

Alter, C. "An Exploratory Study of Conflict and Coordination in Interorganizational Service Delivery Systems," in Academy of Management Journal, 1990, Vol. 33, No. 3; pp. 478-502.

Anarella, J., & Bergmann, C. (1989). Community participation in the development of a five-year plan on AIDS: New York State's process and significant findings. International Conference on AIDS, abstract T.H.P.33.

Baker, M.A., & Schall, S.M. (1990). Shifting to HIV disease as a basis for planning services in New York City. American Public Health Association annual meeting.

Baker, P.M. (1981). Social coalitions. American Behavioral Scientist, **24**, 633-647.

Carrick, R., Coleman, D., & Zelinski, D. (1989). Developing an integrated and comprehensive local community response to AIDS in a low incidence community. International Conference on AIDS, abstract E.529.

Cummings, T.G. "Transorganizational Development" in Barry Staw and L. L. Cummings (Eds.), Research In Organizational Behavior: An Annual Series of Analytical Essays and Critical Reviews, Vol. 6, 1984; pp. 367-422.

Denitch, B. (1983). Confronting coalition contradictions. Social Policy, **13** (4), 54-55.

Downing, M., Case, P., Clark, G., Dietrich, R., Garcie, D., & Prem, R. (1990). It is better to beg forgiveness, then to ask permission. International Conference on AIDS, abstract 3067.

Fleishman, J.A. (1990). Research issues in service integration and coordination. Community-based care of persons with AIDS: Developine a research agenda, 157-167. Rockville, MD: Agency for Health Care Policy and Research, US Department of Health and Human Services (PHS Publication No. 90-3456).

Fleishman, J.A.; V. Mor; J.D. Piette; and S. Masterson-Allen; Oreanizine AIDS Service Consortia: Lead Agency Identity and Consortium Cohesion, Center for Gerontology and Health Care Research, Brown University. (Undated Article.)

Ferels, J.M., Medina, V., & Sieradzki, M.J. (1988). A strategy for an integrated response to the HIV epidemic in your community. NAN Technical Assistance Series. Washington, DC: National AIDS Network. (Reprinted by American Psychological Association, 1200 17th Street, NW, Washington, DC 20036.)

Ferguson, L.D., & Link, W.E. (1990). Drug abuse and AIDS community education program: Organizing the community to become involved. International Conference on AIDS, abstract F.D.771.

Fullilove, M., Fullilove, R., & Morales, E. (1989). Psychoeducation: A tool for AIDS prevention in minority communities Journal of Psychotherapy & the Family, **6** (1-2), 143-160.

Fullwood, P.C., & Hartfield, K. (1989). AIDS education in communities of color: A private-public partnership model. International Conference on AIDS, abstract M.E.P. 11.

Goldbeck, W.B. (1987). Coalitions that treat health care concerns. Business Insurance, **21** (44), 34-35.

Grose, R., Mann, J., O'Malley, J., & Morrison, K. (1990). Strength in solidarity: Building effective NGO AIDS networks. International Conference on AIDS, abstract F.D. 874.

Hankins, R.W., & Foss, P.J. (1989). Objectives for a system of health care delivery for HIV infected people Socioeconomic Planning Science, **23** (4), 181-193.

Harris, I.M. (1984). The citizens coalition in Milwaukee. Social Policy, **15** (1), 27-31.

Hirsch, M., & Gamrecki, J. (1988). How to start a local group for people with AIDS: A practical handbook for grassroots organizations. Washington, DC: National Association of People With AIDS.

Hodel, D. & Wikinson, S.D. (1990). "Buyers' clubs" and the legitimization of the AIDS treatment underground -- the PWA Health Group as case study. International Conference on AIDS, abstract Th.D.63.

Hostetter, C., Metheny, S., & McMenamin, D. (1989). Community coalition building as a means of improving service systems for people with HIV infection. International Conference on AIDS, abstract M.E.P.49.

Jones, D. C. (1990). The broadening of community advocacy into an effective legislative coalition. International Conference on AIDS, abstract F.D.788.

Kaplan, M. (1986) Cooperation and coalition development among neighborhood organizations: A case study. Journal of Voluntary Action Research, **15** (4), 23-34.

Kenney, J.B., & Riley, P. (1986). The future of coalitions. Business & Health, **4**, (2), 30-34.

Knox, M.D. (1989, Fall). Community mental health's role in the AIDS crisis. Community Mental Health Journal, **25**, 185-196.

Komorita, S.S., & Hamilton, T.P. (1984). Power and equity in coalition bargaining. Research in the Sociology of Organizations, **3**, 189-212.

Koningsberg, C., Jr. (1989). The Broward network for comprehensive care for AIDS: A public health response. Journal of the Florida Medical Association, **76**, 395-398.

Lee, J., Freudenberg, N., & Trinidad, U. (1990). AIDS prevention, service delivery and education through community-based organizations in the South Bronx, New York City. International Conference on AIDS, abstract F.D. 775.

Lloyd, G.A. (1989). AIDS & elders: Advocacy, activism & coalitions. Generations, **13** (4), 32-35.

Miller, L.A., & Bellefeuille, D. (1990). Model system for AIDS planning and program development in a medium sized city with high numbers of minority intravenous drug users. International Conference on AIDS, abstract F.D.777.

Miller, S.M. (1983). Coalition etiquette: Ground rules for building unity. Social Policy, **14** (2)) 47-49.

Mor, V., Piette, J., & Fleishman, J. (1989, Winter). Community-based case management for persons with AIDS. Health Affairs. 139-164.

Mumighan, J.K. (1982). Evaluating theoretical predictions in the social sciences: Coalition theories and other models. Behavioral Sciences, **27** (2). 125-130.

Mumighan, J.K. (1985). Coalitions in decision-making groups: Organizational analogs. Organizational Behavior & Human Decision Processes, **35** (1), 1-26.

Nielson, P.S. Summary Report on Allentown/Lehigh Valley AIDS Long-range Planning Coalition, prepared for NAIEP/CDC in 1991

Oliver, C., "Determinants of Interorganizational Relationships: Integration and Future Directions" in Academy of Management Review, 1990, Vol. 15, No. 2; pp. 241-265.

Pegge, J., Isaacs, G., & Miller, S. (1989). Networking: A prevention and care strategy for the gay minority in South Africa. International Conference on AIDS, abstract **T.E.O.15**.

Phair, J. (1989). AIDS Strategic Plan for the City of Chicago. Chicago Department of Health, 50 West Washington, Street, Room 228, Chicago, IL 60602.

Ralin, P.L., Holbrook, D., & Peterson, M. (1989). AIDS coalition for education (ACE): A broad-based organization for the coordination of AIDS education, information and prevention efforts. International Conference on AIDS, abstract T.E.P.58.

Riley, D., McCrimmon, M., & Sheyke, K. (1989). AIDS and substance use education and prevention: A community-based approach. International Conference on AIDS, abstract Th.D.P.85.

Robert-DeGennaro, M. (1986). Building coalitions for political advocacy. Social Work, **31**, 308-3 11.

Rose, S.M. (1986). Community organization: A survival strategy for community-based empowerment-oriented programs. Journal of Sociology and Social Welfare, **13**, 491-506.

Ryndes, T. (1989). The coalition model of case management for care of HIV-infected persons. Quality Review Bulletin, **15**, 4-8.

Schouten, J., Thombum, K., Diamond, M., Kendro, B., Partika, N., Peak, A., & Starbuck, G. (1990). A community based effort to establish legal needle exchange in the state of Hawaii. International Conference on AIDS, abstract F.D.772.

Segal, J. (1981). Coalition formation and players' incentives. The Journal of Psychology, **108**, 261-266.

Sink, D.W., & Stowers, G. (1989). Coalitions and their effects on the urban policy agenda. Administration in Social Work, **13** (2), 83-98.

Sofaer, S., Coalitions and Public Health: A Program Manager's Guide, (Washington: Academy for Educational Development), 1992, for further introductory reading on theoretical frameworks of coalitions.

Staggenborg, S. (1985). Coalition work in the pro-choice movement: Organizational and environmental opportunities and obstacles. American Sociological Association annual meeting.

Urwitz, V., Ohgren, M., Juvall, T. (1989). The Futures Workshop as a method for mobilization and coordination in AIDS prevention. International Conference on AIDS, abstract Th.E.0.5.

Van de Ven, A.H. and Ferry, D.L. Measuring and Assessing Organizations, (New York: John Wiley & Sons).

Weisner, S. (1983). Fighting back: A critical analysis of coalition **building** in the human services. The Social Service Review, **57**, 291-306.

Wohlfeiler, D., Segura, A., & Procupet, A. (1989). World AIDS Day activities and their significance for AIDS prevention in Catalonia. International Conference on AIDS, abstract E. 674.